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Caring for Your Lymphedema: A Guide to Everyday Action

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CARING FOR YOUR LYMPHEDEMA:

A GUIDE TO EVERYDAY ACTION

by

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Sonia Zimmerman
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PERMISSION

Title	Taking Care of Your Lymphedema: A Guide to Everyday Action
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ABSTRACT

This purpose of this scholarly project is to present a workbook that assists patients with lymphedema and their therapists to develop a home management program that can successfully be integrated into the patient's daily occupations. The workbook utilizes the principles of the Occupational Adaptation theoretical frame of reference to guide the patient through the steps of making an adaptive response to the occupational challenge of lymphedema management. A review of the literature describes the physical aspects, psychosocial aspects, and the lived experience of the person with lymphedema. The literature review also indicates that currently the preferred method of treatment for lymphedema is combined decongestive therapy (CDT). CDT teaches the patient the occupational readiness skills that are necessary for successful management of lymphedema, however does not address the integration of those skills into everyday occupations or development of skills for positive coping. In addition, insurance companies in the United States have also limited the amount of time and the type of treatment that can be provided to patients with lymphedema. The scholarly project presents a workbook that can be used concurrently with the manual lymphatic drainage portion of CDT to promote development of an individualized plan to manage lymphedema, integration of that plan into everyday occupations, and development of skills for positive coping.

CHAPTER I

INTRODUCTION

Historically, lymphology and lymphedema in particular have been "overlooked" by the medical community in the United States (Thiadens, 1998, p. 2864). Recently, however, there has been improvement in the options for treatment as well as the availability of trained professionals to provide that treatment (Thiadens, 1998). Occupational therapists and occupational therapy assistants as well as physical therapists, physical therapy assistants, massage therapists, nurses, and physicians are pursuing the advanced training necessary for conservative treatment of lymphedema.

At the current time, the overall preferred method for treatment of lymphedema is combined decongestive therapy (CDT). This is a conservative treatment consisting of massage, compression bandaging, specific exercises, skin care techniques, preventative recommendations, and use of compression garments for day and night wear (Kasseroller, 1998; Kurz, 1986; Wittlinger & Wittlinger, 1998; Földi & Földi, 1991/1993; Burt & White, 1999; Brennan & Miller, 1998; Rinehart-Ayres, 1998; Földi, 1998; Leduc, Leduc, Bourgeois & Belgrado, 1998; Kasseroller, 1998; Casley-Smith, Boris, Weindor & Lasinski, 1998; Lerner, 1998; Földi, Földi, & Kubik, 2003; Zuther, 2005). Occupational therapists as well as other professions have embraced this conservative treatment and integrated it into lymphedema management programs. While CDT is able to control lymphedema, it does not address the need for a patient to make the adaptational response necessary to integrate CDT skills into his/her everyday experience. Thus, the patient may

learn the skills necessary to control his/her lymphedema but may not be able to integrate them into his/her daily life without assistance. The review of literature also indicates that there is a lack of information on this topic.

The occupational adaptation model can be used to formulate occupational therapy interventions to address this shortfall in treatment. A workbook used as homework that allows the patient to address the steps for occupational adaptation to promote relative mastery of patient-identified occupational activities within the individual environment of the patient would allow both the patient and the therapist to address this issue. Occupational therapy is uniquely situated to provide this treatment option for persons with lymphedema and to educate other treating professions about the importance of occupation with this population.

The intent of this scholarly project is to develop a workbook that allows patients with lymphedema to use the Occupational Adaptation theoretical frame of reference to develop a plan to manage his/her lymphedema by incorporating CDT into his/her everyday experience.

Chapter II presents a literature review, which allows the reader to understand research on this topic as well as what is lacking in the literature. Chapter III is an overview of the process used to develop the project and product. Chapter IV presents the product, a workbook that uses occupational adaptation principles to assist the patient in developing a plan and the coping skills necessary to successfully manage his/her lymphedema. All forms and educational handouts necessary for implementation of the workbook in practice are included. This workbook is intended to be used in conjunction with CDT. The principles of CDT are overviewed but not presented in depth as training

in this treatment protocol is beyond the scope of this project. Chapter V includes a summary and conclusions in regards to the product, any limitations, and recommendations for the future. Appendices follow and include an example of the Occupational Adaptation theoretical frame of reference and a sample occupational therapy evaluation form that incorporates the principles of occupational adaptation. Finally, reference list of all sources in cited in the project is provided.

CHAPTER II

REVIEW OF LITERATURE

Lymphedema is an accumulation of protein rich fluid in the body's tissues caused by dysfunction of the lymphatic system. The dysfunction causes a decrease in lymphatic transport capacity which causes protein rich fluid to remain in the tissues rather than being transported through the body by the lymphatic system. Lymphedema is not like other forms of edema in the body. Edema in the body is often a symptom of some other disease, for example kidney failure. Lymphedema is a "disease arising as a consequence of a low output failure of the lymphatic system" (Földi, 1998, p. 2833). It does not respond to diuretics (Kasseroller, 1998). Lymphedema can occur in any body part but is often seen in either the upper or lower extremities

Lymphedema can present in either a primary or secondary form. The primary form is caused by congenital abnormalities of the lymphatic system that are present at birth. The lymphatic system may function for a time after birth or it may not function at all. Thus there are two subtypes of primary lymphedema: Type I Nonne-Milroy and Type II Meige. Type I is familial and occurs at birth or shortly thereafter. Type II is also familial and is manifested during puberty. This type can be further defined by being either praecox which is manifested before age 35 or tardum which is manifested after age 35 (Weissleder, 1997).

Secondary lymphedema is caused by damage to the lymphatic system from surgery or trauma, or radiation. This damage often results in decreased lymphatic

transport capacity which ultimately backs up lymph fluid and creates the lymphedema (Weissleder, 1997). In western societies, this form of lymphedema is often seen after treatment for cancer where lymph nodes are surgically removed for staging and treatment and often followed with radiation. In review of the literature, it is noted that this population of breast cancer patients has the largest amount of research of decreased upper extremity function in relation to lymphedema. It is also noted that studies on functional impairments specifically related to lymphedema without a breast cancer co-morbidity are difficult to locate. Secondary lymphedema can also manifest after an infection with either streptococcus resulting in an erysipelas or filaria resulting in filariasis. Filiariasis is mostly seen in endemic areas of Southeast Asia, Africa, South America, and the Pacific islands. However, with increasing global travel to these areas, increasing amounts of filariasis are being seen in other areas. With streptococcus infections, persons with lymphedema are particularly susceptible, more so than persons with other types of edema. (Weissleder, 1997). Even a simple injury to the skin of a person with lymphedema can present the optimal conditions for a streptococcus infection to start by causing an opening in the skin. This opening allows bacteria to enter the body, thereby beginning the infection. (Weissleder, 1997).

Lymphedema can be a progressive condition which is identified by three stages. Stage I is considered to be reversible. This stage has no fibrosis of the tissues and the tissues remain soft. Pitting can be observed (Kasseroller, 1998). Stage II is spontaneously irreversible and can be treated with appropriate measures. Here the tissues are firmer and only slight pitting can be observed (Kasseroller, 1998). Stage III is called lymphatic elephantiasis. The tissues now present with a fibrotic component. This stage can be

improved with treatment but can not be reversed. Further complications can include collagen fibers increasing, degeneration of elastic fibers, and additional venous congestion (Kasseroller, 1998).

Physical Limitations

In addition to the tissue complications, lymphedema can result in various physical limitations of the areas involved. Lymphedema (swelling), decreased range of motion, decreased strength, pain, neurologic deficits and decreased flexibility are examples of physical limitations described in the literature.

Carson, Coverly, and Lasker-Hertz (1999) studied 30 patients who underwent combined decongestive therapy (CDT) treatments associated with the Columbia/HCA Cancer Care Center. The authors indicated that 47% of participants had restrictions in range of motion mostly in the shoulder area. They also indicated that 60% of participants showed strength deficits in the upper extremity or scapular stabilizing muscles. The range of motion and strength deficits also adversely affected the participants' posture which subsequently adversely affected the lymphedema "due to the fact that normal lymphatic flow is facilitated by normal respiration and muscle activity" (p. 16). Sixty-three percent of the patients identified pain from lymphedema or other complicating factors and 43 % reported neurological deficits including carpal tunnel, gait deviations, balance deficits, motor loss and paralysis.

Hayes, Battistutta, and Newman (2005) indicated that dominance of the treated side is relevant when considering upper body function in this population. They noted that treatment on the dominant side was associated with better upper body functions compared to upper body function for persons treated on the non-dominant side. These

authors also identified that even though the dominant side group had higher strength and range of motion measurements, they perceive their lives as more disrupted and burdensome. The authors identify that this could be related to the lists of do's and don'ts given to women to further prevent lymphedema. This study also indicated that the participants had decreased flexibility in conjunction with radiation treatment, but only on the non-dominant side.

Bosompra, Ashikaga, O'Brien, Nelson, and Skelly (2002) found that 2-4 years after primary treatment for breast cancer 63% of respondents hand some numbness, 35% experienced swelling, 15% had moderate to severe pain in the affected arm, 14% had moderate to severe pain in the chest wall/breast tissue, and 13-34% had some limitation in their arm/shoulder function. They suggest using "patient self report to develop a simple lymphedema-specific tool to monitor the functional status of women living with or at risk for lymphedema" (p. 346).

In 2005, Kärki, Simonen, Mälkiä, and Selfe (2005) studied the impairments, activity limitations and participation restrictions six and 12 months after breast cancer operation. At six months post surgery the most common impairments were, breast scar tightness (45.8%), axilla scar tightness (45.8%), axilla edema (39.6%), and neck/shoulder pain (38.5%). In contrast, at twelve months the most common impairments were axilla scar tightness (36.5%), limb numbness (32.3%), and neck/shoulder pain (40.6%). The incidence of upper limb lymphedema was consistent during the 12 month period at 25-26%. These authors suggest that there is an "urgent need" for developing protocols for patients with breast cancer to "support their functioning and to prevent permanent, limiting disabilities that would affect the health condition" (p. 187).

Hayes, Battistutta, Parker, Hirst and Newman (2004) addressed the task burden of daily activities requiring upper body function among women following breast cancer treatment in 2004. They noted that the top four most burdensome tasks were carrying a moderate weight, washing the upper part of the back, opening a tight jar and fastening a bra. Other burdensome tasks included: carrying a light weight, pushing or pulling a shopping trolley or pram, carrying laundry, vacuuming, mopping, sweeping, raking, placing objects on a shelf above shoulder height, and making a bed. Furthermore, they stated that a diagnosis of lymphedema and level of fitness showed the most consistent relationships with task burden. Increased lymphedema and decreased fitness consistently related to increased task burden. This study was conducted on members on a voluntary mailing list. Not all of the participants had developed or were even at risk for lymphedema. Breast cancer patients often develop lymphedema and may describe some of the same problems with upper body functioning.

The review of literature for this scholarly project does not include similar studies completed solely on persons with the diagnosis of lymphedema as these studies are currently not available in the literature.

Werngren-Elgström and Lidman (2004) studied the incidence of secondary lymphedema of the lower extremities, resulting symptoms, and effect on daily living. The sampled population was a group of women undergoing radiation and surgery for cancer of the uterine cervix. Unilateral rather than bilateral edema was the primary result even though participants underwent a complete pelvic lymphadenectomy. The incidence of lymphedema in the group that received two intracavitary radium treatments was 4% compared to 67% in the group with two or three intracavitary radium treatments. In

addition, 11% experienced pain, 20% stated that they had difficulty finding clothing and shoes that fit, 38% considered that their problems with daily living were serious, and 26% had their leisure activities restricted by the lymphedema (Werngrem-Elgström & Lidman, 2004). The outcome of this study highlights the need for treatment of this population that includes assisting the patient to develop an adaptational response to his/her lymphedema so that the patient is able to adapt to changes in his/her daily living activities.

Overall, the literature reflects that lymphedema has adverse effects on the client factors of body functions and body structures. This adverse effect will subsequently affect performance skills, performance patterns, and ultimately performance in areas of occupation as outlined in the occupational therapy practice framework (AOTA, 2002).

Psychosocial Concerns

Lymphedema does not only produce physical effects but also has psychosocial concerns associated with it. Tobin, Lacey, Meyer, and Mortimer (1993) indicated that breast cancer patients with arm swelling experience greater psychiatric morbidity on measures of both anxiety and depression. Collins, Nash, Round, and Newman (2004) reported that the physical impact of functional impairments leads to psychological strain. The women in the study had difficulty dealing with the constant reminder of their illness and the possibility that they may never have full return. They described difficulty with discomfort while driving and sleeping, posture disturbances, reduced employability in physical work, and decreased ability to complete housework. Also, the group had difficulty emotionally dealing with the possibility of developing lymphedema or the actual development of lymphedema.

Cohen (2005) suggests that occupational therapy specifically can address the psychosocial issues associated with lymphedema by the therapist developing an awareness of the fact that lymphedema causes "drastic changes" to a person's body such as limb swelling, decreased range of motion, and pain (p. 18). These changes need to be examined in conjunction with the anxiety and stress that are inherent in dealing with a life threatening disease such as breast cancer. The physical body changes, anxiety, and stress taken together can indicate decreased body image which can result in decreased "functioning in a variety of life roles" (p. 18).

At the 1998 American Cancer Society Lymphedema Workshop, Passik and McDonald (1998) identified that women who develop lymphedema have higher levels of psychological, social, sexual, and functional morbidity when compared to women with breast cancer who do not develop lymphdema. In addition, "women who have poor social support, pain, lymphedema in the dominant hand, and/or a passive and avoidant coping style report the highest levels of disability" (p. 2817).

The literature indicates overall that lymphedema has a negative effect on the emotional functions and experience of self and time functions included in client factors in the occupational therapy practice framework. This negative effect will subsequently affect performance skills, performance patterns and ultimately performance in areas of occupations (AOTA, 2002).

The Lived Experience of Lymphedema

Persons with lymphedema experience a wide range of both physical and psychosocial issues. To understand a person with lymphedema holistically, it is important to examine that person's lived experience. Williams, Moffatt, and Franks (2004)

described the actual experiences of lymphedema diagnosis and treatment as well as overall coping with lymphedema in their phenomenological study of 15 individuals with different forms of lymphedema. Participants had lymphedema related to breast, cervical, and penile cancers. In addition, participants also had primary lymphedema of the legs and lymphedema of the legs secondary to venous insufficiency. The subjects described feelings of uncertainty regarding the speed at which they were diagnosed with lymphedema. Breast cancer survivors describe that they were more quickly diagnosed with lymphedema in comparison to persons with the primary form who were not diagnosed as quickly. They also describe the experience of anxiety, fear and sorrow. Not being given enough information and tension with health care professionals is also described. Themes of facing social stigma, keeping the lymphedema hidden, communication with others, making sense of the lymphedema and the variety in use of coping strategies are described as reflective of how the lymphedema was experienced by the participants. In response to lymphedema treatment participants discussed the need to "prepare themselves" both physically and psychologically for treatment. The authors also stress that the experience of lymphedema is individual to the person that has it, and no two instances are exactly alike (Williams, et al, 2004).

Fu (2005) studied the importance of determining a breast cancer survivor's intention of managing lymphedema. In a phenomenological study of 12 breast cancer survivors in a Midwest state of the United States, Fu identified four revelatory intentions including: keeping in mind the consequences, preventing lymphedema from getting worse, getting ready to live with lymphedema, and integrating the care of lymphedema into daily life. This study identifies that "women only considered having lymphedema

treatment as one of the actions to achieve the intention of keeping control of lymphedema" (p. 454). Fu further indicates that medical professionals treating patients with lymphedema should focus on the patient's intent to manage his/her lymphedema by making changes to occupational activities instead of compliance with a prescribed treatment program.

Johansson, Holmström, Nilsson, Ingvar, Albertsson, and Ekdahl (2003) describe employed breast cancer patients' experiences of lymphedema in a qualitative study of 12 female subjects at the Lymphoedema Unit of the University Hospital in Lund, Sweden. Three common themes emerged: reactions from others, being bound to the chronic disease, and coping. It is of note that many breast cancer survivors were able to point out positives and negatives with their experience of breast cancer, however were not able to point out any positives about their experience with lymphedema. The authors suggest that the participants might have better participation in treatment if they were prepared for the lymphedema and if their coping skills were strengthened.

Morgan, Franks and Moffatt (2005) reviewed the literature regarding health related quality of life with lymphedema. They reviewed both qualitative and quantitative studies and reported a lack of understanding by health care professionals; poor information provided to patients; shock; fear; annoyance; frustration; and negative body image all caused disruption in lifestyles. Adoption of a coordinated approach to treatment and management, which includes patient support, was recommended.

Ryan, Stainton, Jaconelli, Watts, MacKenzie, and Mansberg (2003) described the experience of lower limb lymphedema for women after treatment for gynecologic cancer. They pointed out that the literature is much sparser regarding lower extremity

lymphedema after gynecologic cancer surgery than upper extremity lymphedema after breast cancer surgery. Women in this study group described triggers for their lymphedema including: incidences of trauma or infection, stasis, and heat. The participants described having difficulty obtaining a correct diagnosis and treatment plan. The lower extremity lymphedema produced changes in lifestyle including financial burden, changes to clothing, and changes to activities including changes in personal relationships and loss of interaction and intimacy with partners.

In summary, the literature identifies that persons with lymphedema experience difficulty with performance in areas of occupation defined by the occupational therapy practice framework (AOTA, 2002). This is due to the disruption of performance skills, performance patterns, context, and activity demands as perceived by the participants.

Treatment of Lymphedema

As the literature indicates, lymphedema causes a variety of physical and psychosocial problems for the individual diagnosed with it. At the current time, the overall preferred method for treatment of lymphedema is combined decongestive therapy (CDT). This is a conservative treatment consisting of massage, compression bandaging, specific exercises, skin care techniques, preventative recommendations, and use of compression garments for day and night wear (Kasseroller, 1998; Kurz, 1986; Wittlinger & Wittlinger, 1998; Földi & Földi, 1991/1993; Burt & White, 1999; Brennan & Miller, 1998; Rinehart-Ayres, 1998; Földi, 1998; Leduc, Leduc, Bourgeois & Belgrado, 1998; Kasseroller, 1998; Casley-Smith, Boris, Weindor & Lasinski, 1998; Lerner, 1998; Földi, Földi, & Kubik, 2003; Zuther, 2005). The National Lymphedema Network regularly updates the accepted Lymphedema Risk Reduction Practices which divides the practices

into sections of: skin care, activity/lifestyle, avoidance of limb constrictions, compression garments, avoidance of extremes of temperature, and additional practices specific to lower extremity lymphedema (National Lymphedema Network, 2006). The National Lymphedema Network also publishes and updates position papers on risk reduction, air travel, and exercise which are also helpful in the CDT process (National Lymphedema Network, 2006). These risk reduction practices are the core of the preventative measures described above.

Intermittent pneumatic pumps have also been used. Surgical therapy can consist of debulking, lipectomy, and a variety of surgical techniques that are believed to improve the removal of lymph. Each of these procedures does have significant risks for patients including poor wound healing, infection, and return of edema. Certain pharmacological agents have been used to decrease lymphedema, however these drugs have not been approved by the Federal Drug Administration of the United States due to adverse side effects. Antibiotics are used to treat infections, such as streptococcus infections, associated with lymphedematous limbs (Brennan & Miller, 1998).

Few studies of the outcomes of CDT are reflected in the current literature. Casely-Smith, Boris, Weindorf, and Lasinski (1998) describe the reductions achieved through the Adelaide Lymphedema Clinic as being an overall average of 64% reduction for the first 78 upper extremities to pass through the clinic. The literature, however, does suggest that treatment is effective at overall reduction of limb volume (Kasseroller, 1998; Kurz, 1986; Wittlinger & Wittlinger, 1998; Földi & Földi, 1991/1993; Burt & White, 1999; Brennan & Miller, 1998; Rinehart-Ayres, 1998; Földi, 1998; Leduc, Leduc,

Bourgeois & Belgrado, 1998; Kasseroller, 1998; Casley-Smith, Boris, Weindor & Lasinski, 1998; Lerner, 1998; Földi, Földi, & Kubik, 2003; Zuther, 2005).

Specifically in the United States, reimbursement of treatment has become an issue. Medicare in particular has put many restrictions on what lymphedema therapists can bill for patient treatment. The focus of treatment must be on assisting the patient to be independent in self-care with CDT rather than reduction of the limb itself. Therapists treating patients under the Medicare program benefit however are not allowed to bill for the education time in excess of bandaging and exercise necessary to adequately educate the patient in the skills necessary to implement CDT in an independent fashion (CAHABA GBA, 2005 & 2006). Private insurance carriers will vary in their coverage but often use Medicare guidelines as a basis.

CDT is currently the overall preferred method of conservative treatment for lymphedema. CDT teaches the patient how to physically care for his/her limb however, does not address the patient's ability to cope with and produce an adaptational response toward his/her lymphedema. Insurance regulations further decrease the ability of the person with lymphedema to receive appropriate care by not covering intervention methods to address coping and production of an adaptational response. Thus, it becomes necessary to develop an educational tool to be used as independent homework to assist the patient in developing the skills necessary to integrate CDT into his/her experience of everyday life. A workbook applying principals of occupational adaptation will enable the patient to develop the adaptational skills necessary to positive coping.

Theoretical Background

In order to consider development of a workbook applying principals of occupational adaptation with persons with lymphedema, it is necessary to establish the theoretical basis for intervention with this population. Occupational Adaptation was first described by Schultz and Schkade in 1992 as part of a holistic approach to occupational therapy evaluation and intervention with diverse populations. This theoretical frame of reference describes a normative process in individuals and can serve as a guide for planning and implementing treatment (Schkade & McClung, 2001). The roles an individual takes on in his/her life are the foundation of his/her occupational functioning. Different life roles are made up of different tasks that need to be addressed in order to be successful. When a life role changes, the tasks necessary to that role will change and the individual will need to make an adaptational response. The "demand on the occupational adaptation process is greatest when the individual must transition to changing life roles." (Schkade & McClung, 2001. p. 2). If a transition is large, such as a person learning to function in areas of occupation after a stroke, the occupational adaptation process is at greater risk for dysfunction than if the transition is smaller, such as a student writing a one page paper for a class. When the occupational adaptation process is dysfunctional the individual is at risk for dysfunction in engagement in occupation to support participation in context as outlined by the occupational therapy practice framework (AOTA, 2002).

Persons with diagnosed with lymphedema face a large transition in life roles. Lymphedema has the potential to negatively affect physical aspects of functioning, psychosocial aspects of functioning, and ultimately the lived experience of daily life. Lymphedema can affect all the aspects of engaging in occupational activities including

the client factors, activity demands, context, performance skills, performance patterns, and performance in areas of occupation as defined by the occupational therapy practice framework (AOTA, 2002). The individual diagnosed with lymphedema is in need of instruction in the occupational readiness skills contained in traditional combined decongestive therapy (CDT), however, he/she is also in need of instruction in the occupational adaptation process to assist him/her in making an adaptive and masterful response to this changing role. This need for an adaptive and masterful response indicates that the occupational adaptation theoretical frame of reference would effectively address the needs of the population of persons diagnosed with lymphedema.

Occupational adaptation was developed as a normative process to address a wide range of persons with occupational dysfunction states. Occupational Adaptation has been applied to various populations including hip fracture (Jackson & Schkade, 2001), shift workers (Walker, 2001), adolescents with limb deficiencies (Pasek & Schkade, 1996), level II occupational therapy fieldwork (Garrett & Schkade, 1994), and patients with cerebrovascular accident (Gibson & Schkade, 1997). In review of the literature, application of occupational adaptation to persons experiencing occupational dysfunction due to lymphedema could not be located.

Summary

Lymphedema can have a negative effect on physical aspects, psychosocial aspects, and the lived experience of persons with lymphedema. The negative effect in these areas contributes to a decrease in engagement in occupation to support participation in context as defined by the occupational therapy practice framework (AOTA, 2002). Lymphedema care has historically addressed the occupational readiness skills that are

necessary for independent self-care; however, occupational activity has largely been ignored. Reimbursement regulations have further curtailed both the occupational therapist's and the patient's abilities to address the occupational dysfunction that occurs as a result of lymphedema. Due to these circumstances, a workbook used as homework that allows the patient to address the steps for occupational adaptation to promote relative mastery of patient-identified occupational activities within the individual environment of the patient is necessary.

CHAPTER III

PROCESS

A search of the literature was completed using OT search, PubMed, and CINAHL. The National Lymphedema Network website was used to gather information on position statements as well as for books containing information relevant to this project. The literature review provided a definition of lymphedema including stages and progression, physical limitations and psychosocial concerns related to lymphedema, descriptions of the lived experience of lymphedema, current accepted treatment methods, and the theoretical basis of occupational adaptation for this product. The literature review also revealed that there currently is a focus on the occupational readiness skills of caring for lymphedema in the treatment protocols, however, the ability to make an adaptational response is not a focus of those treatment protocols. Also, in the United States, funding for treatment of lymphedema for persons with Medicare must focus on making the patient independent with self-care, while not funding the educational process needed to assist the patient with making an adaptational response. Thus a workbook used as homework that allows the patient to address the steps for occupational adaptation to promote relative mastery of patient-identified occupational activities within the individual environment of the patient is necessary.

A person diagnosed with lymphedema faces a large transition in roles in order to care for his/her lymphedema over a lifetime. The person also needs to respond

adaptively and masterfully to this transition of roles. The occupational adaptation theoretical frame of reference provides the patient and the treating therapist with a framework from which an adaptational response can be identified in the form of a plan to manage lymphedema. Thus, the occupational adaptation theoretical frame of reference serves as a guide for the activities in the workbook. The use of the occupational adaptation frame of reference for initial evaluation and subsequent treatment through use of the workbook combined with traditional combined decongestive therapy (CDT) assists the patient to not only develop a plan to manage his/her lymphedema, but also teaches him/her the sensorimotor and psychosocial skills that are necessary for success.

Chapter I provides the patient with basic information about lymphedema. Chapter II outlines lymphedema management essentials including the do's and don'ts of lymphedema care. Chapter III provides an overview of treatment as well as sections for the patient to write down schedule information and goal. Chapter IV of the workbook contains the actual exercises that follow the occupational adaptation frame of reference and are designed to assist the patient in developing a plan to care for his/her lymphedema under the guidance of the treating therapist. Chapter V contains the additional exercises that are designed to increase the coping skills necessary for long term management of lymphedema. Chapter VI allows the patient to examine the plan that he/she has created prior to discharge from the treatment program. Additionally, Chapter VII instructs the patient on how to re-evaluate his/her plan periodically after discharge from the treatment program. A list of other resources that may be of interest to the patient is provided as well as a list of references for the project.

The scholarly project concludes with a summary of the literature review and product. In the appendices, an example of Occupational Adaptation in action is provided. Also, an example of an initial evaluation form is provided for a treating therapist. It incorporates a traditional CDT evaluation with occupational adaptation principles to establish the holistic view of the patient necessary for treatment planning. The initial evaluation form is not included in the product as it is not a handout for the patient; rather, it is intended to assist the therapist with the documentation process. A reference list is included with all resources used throughout the project.

The product, a workbook to assist patients in developing a successful adaptational response to his/her lymphedema management, is meant to be used in an established lymphedema management program in an occupational therapy department. The treating occupational therapist should be knowledgeable in both CDT and occupational adaptation. The workbook is designed to be used as homework and discussed concurrently with manual lymphatic drainage, however, can be used consecutively in adjunct to CDT treatment. Occupational therapy is uniquely positioned to assist persons diagnosed with lymphedema to make an adaptational response necessary for successful management of lymphedema as well as to educate other professions treating this population as to the importance of occupation.

CHAPTER IV

PRODUCT

Program Description

This project presents an educational tool to be used as homework to assist a patient with lymphedema to develop the skills necessary to integrate combined decongestive therapy (CDT) into his/her experience of everyday life. The product is a workbook that applies the principals of occupational adaptation to this population, thereby enabling the patient to develop the adaptational skills necessary to develop a plan to manage his/her lymphedema as well as positive coping. This product is used in an established lymphedema management program within an occupational therapy department. The goal of this combined program is to promote independent self-care of lymphedema according to CDT principles by assisting the patient to develop an adaptive occupational response to the occupational challenges presented by a diagnosis of lymphedema by creating a plan to manage his/her lymphedema and developing positive coping. Occupational Adaptation will be used to promote the occupational response described above.

Admission Criteria

The people using this workbook are participants in a lymphedema management program run by occupational therapists within an established clinic setting. Therefore, the patients will need to be referred to the program by a physician, physician assistant, or nurse practitioner (per state guidelines) with a diagnosis of lymphedema.

Treatment Process

Upon admission to the program, each patient receives an individualized assessment of his/her lymphedema, activities of daily living, independence in self care of lymphedema, psychosocial issues, and past treatment. Please see appendix B for an example form. The assessment establishes a plan of treatment that most likely includes combined decongestive therapy to decrease the size of the lymphedema and education to increase independence in self care of lymphedema. At this point the patient in conjunction with the therapist begins using the workbook presented here to assist in the development of adaptational skills necessary to successfully integrate the CDT into everyday life and to develop positive coping skills.

Assessment

Each patient referred to the program will receive an individualized assessment to evaluate him/her holistically. With the Occupational Adaptation theoretical frame of reference in mind, this population is at risk for dysfunction in the person systems of sensorimotor and psychosocial as listed in figure 1 if integration of CDT techniques into everyday life does not occur based on information presented in the literature review.

Figure 1: Person Issues

Sensorimotor Issues	Psychosocial Issues	Cognitive Issues
• Edema • Range of Motion Deficits • Strength Deficits • Pain • Neurological Deficits • Flexibility Deficits • Cellulitis	• Anxiety • Depression • Coping Skill Deficits • Negative Body Image • Social Morbidity • Sexual Morbidity • Shock • Fear • Annoyance	• Deficits in this area are not described in the literature, however, decreased cognition can affect a person's ability to recall instruction and follow through with a treatment plan.

Each of these person systems is evaluated with the genetic, environmental, and phenomenological subsystems in mind. For example: genetically, does he/she have short arms that would prevent him/her from massaging all the necessary areas? Does his/her ongoing environmental circumstances predispose him/her to not being able to afford replacement bandages? Has the patient had any past negative experiences with treatment that would interfere with this course of therapy in a phenomenological way?

The therapist also assesses for possible dysfunction within the occupational environments of work, play/leisure, and self-care. Each of these environments is unique and has unique influences upon the patient that need to be explored. Also, each of these environments is evaluated with the physical, social, and cultural subsystems in mind. For example: is the patient's work station set up properly in the physical sense so that bad postures that contribute to lymphedema can be avoided? Does the person's social environment allow for the wearing of a compression sleeve without undue questioning? Culturally, are there any customs or rules that may preclude the patient from not carrying heavy items with his/her involved limb? All of these issues are addressed in a thorough evaluation in order to understand the press for mastery that is occurring with each individual patient.

In addition, the occupational therapist utilizes edema measurements and tracking (circumferential measurements taken every four centimeters along the limb from a consistent starting point and converted into liters), range of motion testing, manual muscle testing, sensory screening, use of pain scale, neurological testing as necessary, and a semi-structured interview. From this data, a treatment plan is identified in conjunction with the patient. Once the treatment plan is established, the patient will begin

CDT. At the end of the session, the patient is introduced to the workbook, asked to complete an assignment at home and bring the workbook back for the next session. At the next session, the outcome of the assignment is discussed while the patient is receiving the manual lymphatic drainage portion of CDT. This pattern continues while the patient is receiving treatment. The workbook promotes an adaptive response within the patient which enables the patient to develop a plan to manage his/her lymphedema and integrate that plan into his/her daily occupations.

Goals and Objectives

Lymphedema management programs typically address goals to increase patient independence in self-care as described in figure 2.

Figure 2: Goals of Established Lymphedema Management Program

• Increase patient independence with self care of lymphedema including: - Increasing independence with self manual lymphatic drainage - Increasing independence with self bandaging - Increasing independence with skin care techniques - Demonstrating understanding of lymphedema precautions (Do's and Don'ts"
• Increase patient independence with use of both day and night compression garments including: - Selection of appropriate garments - Wear and care of garments

The workbook addresses a patient's ability to develop an adaptational response resulting in relative mastery over the CDT skills taught in the treatment program (Figure 3).

Figure 3: Added Goals

• Development of a written plan to incorporate CDT skills into daily occupations
• Increase independence with incorporating CDT changes into daily activities including: - Increasing patient's experience of relative mastery - Increasing generalizations of lymphedema care to novel tasks - Increasing patient's spontaneous initiation of adaptation not specifically suggested by therapist

By implementing these additional goals, focus of treatment can extend from teaching of skills to implementation of adaptive responses that will assist the patient in developing lifestyle changes.

Intervention

The workbook is designed to be used in addition to standard CDT training to guide the patient in adapting the principles of CDT into his/her daily lifestyle. In established lymphedema programs, usually an evaluation of the patient takes place followed by intervention with CDT. A patient can expect to have manual lymphatic drainage completed for a minimum of 30-45 minutes followed by bandaging with short stretch compression bandages. The entire session runs 60-75 minutes in length depending upon the patient. Treatment sessions occur with a frequency of five times per week and duration of two to four weeks. Insurance changes have limited the actual amount of time that can be spent with a patient educating him/her as to all of the necessary changes that need to be incorporated in order for a lymphedema reduction to be successfully maintained. Of note, however, is that those same insurance changes also mandate that the focus of the treatment session is not to reduce the lymphedema, but rather, to make the patient independent in self-care. This presents a quandary for both the therapist and the patient. How can reduction of the lymphedema to a self-manageable post treatment level be achieved while educating the patient to achieve independence when one objective is deemed not the focus of treatment while the other is non-covered? One answer is to incorporate a workbook used as homework during the course of the treatment time spent in manual lymphatic drainage. In this situation, discussion and exploration of emotions and concerns brought to light by the homework between sessions

would occur simultaneously with the manual lymphatic drainage. The workbook allows the therapist and the patient to explore the adaptive response sub-processes related to integrating occupational adaptation with regards to lymphedema control. With this type of intervention, it is expected that the therapist be well-trained in manual lymphatic drainage as well as occupational adaptation. This workbook allows the focus of treatment to be shifted to occupation and occupational activity rather than the occupational readiness skills that are currently the center of treatment.

Caring For Your Lymphedema: A Guide to Everyday Action©

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Introduction

Lymphedema can affect your life by disrupting your daily occupations. Occupations are defined as "activities of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything that people do to occupy themselves, including looking after themselves...enjoying life...and contributing to the social and economic fabric of their communities..." (Law, Polatajko, Baptiste, and Townsend, 1997, p. 30). The physical aspects of lymphedema can be managed with the use of combined decongestive therapy (CDT). However, CDT can be time consuming and, at times, can also be disruptive to your daily occupations. In, order to successfully integrate CDT with your occupations, it is important to formulate a plan to manage your lymphedema. This workbook is designed to assist you in developing that plan.

Chapter I gives you an overview of lymphedema, including definitions and current treatment methods. Chapter II contains the dos and don'ts of lymphedema management. Chapter III describes a typical treatment day and provides you with the tools to organize your treatment. In chapter IV, activities are used to help you develop an adaptational response and ultimately a plan to manage your lymphedema. Chapter V contains activities that help to develop your coping skills. Chapter VI guides you through the process of evaluating your plan to determine if it needs any final changes before your discharge from treatment. The activities in Chapter VII are used after treatment to determine if your plan is still working or if you need to make changes. Finally, chapter VIII contains additional resources that you may find helpful.

Central to all the activities in this workbook is the occupational therapy theory of Occupational Adaptation by Schultz and Schkade (1992). The core of this theory is that all people face occupational challenges everyday. In order to address these challenges, people move through a set pattern to develop an adaptational response (Schkade & McClung, 2001). By following this pattern, you and your therapist will develop a plan that works for you.

This workbook will also help you understand lymphedema, how it occurs, and what you can do now. You can take control of your lymphedema and the following information in conjunction with treatment from a trained lymphedema specialist can help.

How to Use This Book

This book is designed to work in conjunction with combined decongestive therapy (CDT) provided by a trained lymphedema therapist. Your therapist will assign you homework at the end of each treatment session. The homework should be completed prior to your next treatment session as it will be discussed at that time with your therapist.

The homework activities are designed to assist you with the process of developing your own, unique plan to manage your lymphedema. The activities provided in chapter IV will be used in the order they appear in this book. The activities in chapter V however can be individualized to you. As such, don't be alarmed if you are not asked to complete all of these activities.

This book also allows you to reflect on your plan to manage your lymphedema both at the end of your formalized treatment with a therapist and periodically thereafter. This reflection allows you to adjust your plan as your life circumstances change.

During the course of your treatment, don't be afraid to ask your therapist any questions you may have.

Chapter I

Important Information About Lymphedema

To begin with, what is Lymphedema?

Lymphedema is the accumulation of water and protein in the tissues located just below the skin resulting from poor or abnormal drainage of fluid through the lymphatic system. Lymphedema is classified into two types: primary or secondary (Zuther, 2005).

Primary lymphedema is thought to result from an inherited abnormality of the lymphatic system such as hypoplasia (decreased number or size of lymphatic vessels) or hyperplasia (too many lymphatic vessels which do not function properly) (Weissleder & Schuchhardt, 1997).

Secondary lymphedema is the result of damaged or blocked lymphatic vessels caused by surgery, radiation therapy, injury, limb paralysis, infection, or an inflammatory condition. Surgery combined with radiation therapy for breast cancer is a common cause of upper arm secondary lymphedema for women in the United States (Weissleder & Schuchhardt, 1997).

Each type of lymphedema results in an impairment in the ability of the lymphatic vessels to transport lymphatic fluid. When the impairment becomes too great, the lymphatic fluid will exceed the transport capacity of the vessels and an abnormal amount of protein rich fluid collects in the tissues of the affected area. Left untreated, this stagnant, protein-rich fluid reduces oxygen availability in the tissues and vessels, interferes with wound healing, and provides a culture medium for bacteria that can result in infections (lymphangitis) (Kasseroller, 1998).

Lymphedema should not be confused with edema resulting from venous insufficiency, which is not lymph-edema. However, untreated venous insufficiency can progress into a combined venous/lymphatic disorder, which is treated in the same way as lymphedema (Kasseroller, 1998).

What is the function of the lymphatic system?

The circulatory (blood) system is comprised of two separate components: the venous system which returns blood to the heart, so that it can pass through the lungs to get oxygen, and the arterial system which delivers the oxygenated blood to the tissues. The lymphatic system, however, works on a one-way principal, the purpose of which is to drain lymphatic fluid from the tissues, where it collects (Kurz, 1997).

Lymphatic fluid, also called lymph, consists of five components: protein, water, dead cells, toxins, and some fats. Approximately half of the total protein found in the blood and 1-2 liters of the water that escapes from the bloodstream into the tissues each day are returned to the bloodstream through the lymph. If the lymphatic system did not return this fluid to the bloodstream, it would

collect in the tissues (such as the feet or legs) resulting in swelling. In addition, the lymphatic vessels of the intestines are the only location capable of absorption of certain fatty acids. Finally, the lymph nodes filter this lymphatic fluid to remove cell debris, cancer cells, bacteria, and toxins from the tissues, before the remaining fluid is deposited into the major vessels of the venous system (Kurz, 1997).

What causes lymphedema?

Primary lymphedema, which can affect from one to as many as four limbs and/or other parts of the body, can be present at birth, develop at the onset of puberty, or in adulthood (around age 35). All of these develop from unknown causes, or are associated with vascular anomalies from syndromes such as Turner's, Noonan's, and Klippel-Trénaunay-Weber (Zuther, 2005).

Secondary lymphedema, or acquired lymphedema, can develop as a result of surgery, radiation, infection, or trauma. Specific surgeries such as surgery for melanoma or breast, gynecological, head and neck, prostate, testicular, bladder, or colon cancer (all of which require removal of lymph nodes), put people at risk of developing secondary lymphedema (Weissleder & Schuchhardt, 1997).

Secondary lymphedema can develop immediately post-operatively or weeks, months, or even years later. It can also develop when chemotherapy is administered to the already affected area (the side on which the surgery was performed) or after repeated aspirations of a seroma (a pocket of fluid which occurs postoperatively) in the axilla, around the breast incision, or groin area. This often causes infection and subsequently, lymphedema (Weissleder & Schuchhardt, 1997).

Aircraft flight has also been linked to the onset of lymphedema in patients post-cancer surgery (likely due to the decreased cabin pressure). If have secondary lymphedema, always be sure to wear a compression garment (sleeve, stocking) when you fly, even if you are only considered at risk for lymphedema (Zuther, 2005).

Radiation therapy, used in the treatment of various cancers can damage otherwise healthy lymph nodes and vessels, causing scar tissue to form which interrupts the normal flow of the lymphatic fluid. Radiation can also cause skin dermatitis or a burn similar to sunburn. It is important to closely monitor the radiated area for any skin changes, such an increased temperature, discoloration (erythema) or blistering which can lead to the development of lymphedema (Földi, Föidi, & Kubik, 2003). Be sure to keep the area soft with lotion recommended by your radiation oncologist.

Lymphedema can develop after an infection (lymphangitis) which interrupts normal lymphatic pathway function. A severe traumatic injury in which the lymphatic system is interrupted and/or damaged in any way may also trigger the onset of lymphedema (Weissleder & Schuchhardt, 1997).

What are the symptoms of lymphedema?

"Symptoms of lymphedema can include pain, numbness, a loss of mobility, a loss of skin elasticity, hardening of the skin, increased susceptibility to infection, chronic ulceration of the skin and

swelling that can make an arm, leg, or other body part as much as two, tree, four, or even more times its normal size" (Swirsky & Sackett-Nannery, 1998, p. 5). The onset of lymphedema can feel like fullness or pressure, a pins-and-needles sensation, pitting of the skin, bursting sensation, and/or an aching sensation (Burt & White, 1999). A person with lymphedema may also notice "negative emotional reactions" which can "damage relationships, undermine commitment to necessary self-care, or decrease quality of life" when not addressed properly (McMahon, 2005, p. 3).

The symptoms of lymphedema gradually progress through three stages:

Stage I, or reversible lymphedema, is marked by swelling which is usually reduced with simple elevation of the swollen arm or leg. There is also pitting of the overlying skin when it is depressed (Kasseroller, 1998).

Stage II is referred to as spontaneously irreversible lymphedema and is marked by an increase in fibrous tissue and progressive skin hardening. There can be frequent infections, swelling is increased, and the skin no longer pits when depressed meaning that when pressed by fingertips the tissue bounces without any indentation forming. Simple elevation is no longer effective in reducing swelling at this stage (Kasseroller, 1998).

Stage III, or lymphostatic elephantiasis, shows an extreme increase in swelling in which the limb becomes columnar (loses definition of the knee and/or ankle). There are more extreme skin changes with increased hardening, and there can be large hanging skin folds. Stage III lymphedema can infrequently be associated with Stewart-Treves Syndrome, a highly malignant angiosarcoma (Kasseroller, 1998).

Infection can also be of major concern with lymphedema. Signs and symptoms of infection may include some or all of the following: rash, red blotchy skin, itching of the affected area, discoloration, increase of swelling and/or temperature of the skin, heavy sensation in the limb (more than usual), pain and in many cases sudden onset of high fever and chills (Zuther, 2005). **If you have any of these symptoms you need to see you physician immediately.**

How is lymphedema diagnosed?

Diagnosis is often made through identification by a physician of the signs and symptoms noted above. History of the swelling, measurements, and/or observation of the symptoms is sufficient for diagnosis in most cases. In a small amount of people, symptoms can be non-specific making diagnosis more difficult. When necessary, CT or MRI scans can be used to image lymph nodes and show edema or fibrosis (Weissleder & Schuchhardt, 1997).

Lymphangiography, an X-ray of the lymphatic system after injection of an oil-based contrast dye, is no longer used because it is thought to sometimes damage the remaining functional lymphatic vessels. Lymphoscintigraphy, an alternative imaging technique that utilizes a water-based dye, is now considered to be the safest and most accepted method of diagnostic testing for lymphedema (Weissleder & Schuchhardt, 1997).

What treatments are available for lymphedema?

Although there is presently no cure for lymphedema, treatment can delay or even prevent its progression to a more severe stage.

The most widely accepted treatment for lymphedema is **Combined Decongestive Therapy** (CDT). It involves several components, which at first establish drainage of the lymph, and then maintain and improve the results of the initial intensive phase. The first component of CDT is decongestion or **manual lymphatic drainage** (MLD), which utilizes daily gentle massage and exercises to improve the flow of the lymph. Compression therapy then prevents the reaccumulation of fluid by tightly wrapping the limb following each MLD session (Kasseroller, 1998).

Once maximal reduction in swelling has been achieved, a compression sleeve or stocking is fit to the limb. This occurs after two to four weeks of daily (Monday through Friday) CDT treatments. Home programming consists of meticulous skin care to avoid infections, daily remedial exercises performed while wearing the compression garment to improve muscle tone and help propel the flow of lymph, and self MLD and bandaging (Kasseroller, 1998).

The MLD portion of CDT is absolutely contraindicated if a person has any history of:

- Congestive heart failure (right sided heart insufficiency)
- Blood clots in his/her legs (deep vein thrombosis) within the last 6 months
- Acute infection with a fever
- Untreated cancer (Kasseroller, 1998)

Surgery is occasionally used to treat severe cases of lymphedema. However, it is not usually treatment method of choice for patients with mild or even moderate symptoms. Non-surgical treatments are thought to provide greater relief with fever complications. Since infections can intensify the symptoms of lymphedema, antibiotics may be prescribed in individuals with frequent infections to reduce this risk (Brennan & Miller, 1998).

In addition, **benzopyrones** are a group of drugs, which may provide reduction in lymphedema by aiding in removal of excess protein (Brennan & Miller, 1998). **However**, the sale of these drugs is **not** permitted in the United States and several other countries because several deaths and severe liver damage have been attributed to the use of benzopyrones.

Chapter II

Management Essentials

My schedule is so full. How will I ever fit in all these things I learn in treatment?

Lymphedema can be an overwhelming condition. It requires a lot of your time and attention to take care of your limb. You may need to restructure some of your daily activities to fit in your lymphedema care. Restructuring your routine can be daunting, but it can be done. The activities in this workbook are designed to walk you through the steps of making the changes you need to take care of your lymphedema.

I've heard about the Do's and Don'ts of Lymphedema. What are they?

The National Lymphedema Network (2004 & 2005) has published position statements on lymphedema risk reduction, air travel, and exercise. These publications can be summarized as follows:

1. Try to avoid cuts, bruises, and scrapes to your skin.
2. Try to avoid heat
3. Try not to overdo when you are completing exercises or daily activities such as vacuuming, washing windows, and pushing a lawn mower.
4. Wear clothing that is loose fitting and doesn't pinch your skin.
5. Eat healthy foods and keep an average weight
6. Follow your lymphedema control program recommended by your doctor or therapist.

The following sections are based upon the position papers published by the National Lymphedema Network.

Why is it important to avoid injuring my skin?

Injuries, even small ones, will hurt lymphatic vessels in the skin. Injuries also cause body fluids to build up in the area and cause more swelling. There are some specific things you can do to protect yourself:

A. Keep the skin of your limb clean and dry. Put on a good lotion daily to keep the skin from cracking open.

B. If the lymphedema is in your leg, wear proper footwear. High heel shoes or shoes that are too tight are not only unhealthy, but they increase the risk of injury to the feet. Do not walk barefoot.

C. Be careful when doing housework or working in the garden. Stay away from sharp, pointed objects such as kitchen knives, scissors or gardening tools. Be careful not to burn yourself when ironing. Try to avoid harsh cleaners and chemicals that could hurt the skin. If your lymphedema is in your arm, always wear an oven mitt when removing hot pans from the oven.

D. Be careful when playing with pets. Scratches and bites can become infected.

E. Stay away from insects and getting bites. Wear an insect repellent when outdoors. A small bug bite can cause an infection of the skin and cause more swelling in your limb.

F. Be careful when doing nail care. Do not cut your nails and cuticles with a scissors. Use a nail file or pumice stone. Do not use fake nails.

G. Do not use make-up or other products that can hurt the skin. Use care with razors to avoid cuts or red spots on the skin.

H. Tell any doctor, nurse, or other medical person taking care of you that you have lymphedema. Do not allow blood to be drawn or blood pressure to be taken from the swollen limb.

I. Use caution when doing exercises or sporting activities. Do not do movements that overstrain or exercises that put extra weight on the swollen limb.

J. If you smoke, do not hold the cigarette with your hand if your arm is swollen.

K. If scratches, cuts, or any opening of the skin occurs: wash the area with soap and water, apply a triple antibiotic ointment, and keep the area covered. If you see any signs of infection (**heat, reddening of the skin, fever, chills, further swelling**), contact your doctor immediately.

Why is it important to avoid heat?

Higher temperatures cause more blood to go to an area. This brings more fluid to the area and causes swelling. Any amount of time greater than 15 minutes can cause more swelling in your limb. With this in mind:

A. Do not use saunas.

B. Do not sun bathe (keep the limb in the shade as much as you can and don't get sunburned), and if you can, try to take vacations in cooler climates. Don't cover yourself with a wet towel when in the sun, it turns into a hot pack on the body. Use a dry towel only.

C. When taking a shower, keep the temperature at about 96 degrees F (34 degrees C). Also avoid putting your limb in water temperatures above 102 F.

D. The swollen limb should not be exposed to:
   - Hot packs, moist heat, hot air or short wave treatments
   - Extreme changes in temperature (hot or cold)
   - Classical Swedish massage—causes more blood flow (with fluid) to the area

Why should I be careful not to "overdo" when I am doing exercises or daily activities?

Exercise is good, but for shorter rather than longer amounts of time so as not to over-tire the swollen limb. You should gradually build up the length and amount of any activity or exercise. Stopping and resting often during the exercise or activity is a good idea. It is also important to drink plenty of fluids (water, sports drink, etc) while doing your exercise or activities. Below are some specific ideas:

A. Walking is an excellent exercise with the proper footwear. If the lymphedema is in your arm, do not let it hang down.

B. Swimming is an excellent exercise that does not cause stress on joints. The water pressure acts as compression to prevent fluid from settling in your limb.

C. Sports such as tennis, golf, cross country skiing or weight lifting are not recommended.

D. Try to avoid carrying heavy bags, a purse or other heavy objects if you have lymphedema in your arm.

E. Knitting and needlepoint should be done only for short amounts of time if the lymphedema is in your arm.

F. If you work in an office, take frequent breaks to stretch and move your arms. Repetitive movements, as at a computer or typewriter can cause swelling in your arm if you have lymphedema in it. If your lymphedema is in your legs, avoid sitting or standing for long periods of time (e.g., take breaks to stand or walk when driving, working at a desk, etc.). When you sit, do not cross your legs (decreases circulation).

G. You should wear a sleeve or stockings for heavy activity such as weight lifting.

What difference does the clothing I wear make?

Clothing that is too tight tends to stop lymph fluid from going to the right areas of the body. If your lymphedema is in your arm, it is important to:

A. Wear a bra that does not cut into your shoulders or binds too tight around the middle if your lymphedema is in the arm. Wear a lightweight prosthesis that fits properly into the bra cup.

B. Do not carry a heavy handbag on the shoulder of the swollen arm.

C. Wristwatches and rings should be comfortable and not be worn for long amounts of time on the swollen arm.

If your lymphedema is in your leg, it is important to remember that:

A. Tight panties, girdles or undergarments tend to cut into the skin. Wear undergarments that are loose and comfortable.

B. Women should avoid garter belts or any tight clothing.

C. Men should ensure that the socks have wide borders and avoid the use of garter belts.

What should I eat to keep an average body weight with my lymphedema?

There is no special diet for lymphedema. However it is important to maintain a normal weight as that helps to keep your swelling under control. Today most nutritionists say that the foods you eat should be:

A. Low in salt (salt tends to make the body keep fluid in).

B. Low in fat (fat tends to keep the fluid in the tissues).

Why is it important to follow the lymphedema control program recommended by my doctor or therapist?

Your doctor or therapist will give you a program that is designed for you. Following the program will help you to keep your swelling down so that there is less swelling of your limb. Don't forget to:

A. Wear your bandages at night and your compression sleeve or compression stockings during the day. Wash bandages and sleeve/stockings at least every 3 days and air dry away from direct sunlight. Check the directions that came with the sleeve/stockings for details.

B. Try to keep the swollen limb above the level of your heart at night at night if you can. Try to sleep so that your body weight is not pressing on the limb (slows circulation).

C. Do the exercises and self-massage you learned daily. Change the way your limb is placed often rather than let the limb stay in the same place for too long.

D. When traveling in an airplane, wrap your limb with compression bandages during the flight.

E. Go to your doctor if you have any signs of infection (**heat, reddening of the skin, fever, chills, further swelling**), or if you have any questions about your swelling.

Chapter III
Your Treatment

Treatment of lymphedema is often referred to as **management** because there is no cure for lymphedema. It is a life long condition that needs to be managed as part of your everyday life. Conservative management with combined decongestive therapy or CDT will probably be recommended by your therapist in conjunction with your physician.

CDT will consist of daily (Monday through Friday) treatment sessions. Each session will follow a similar schedule:

1. Your bandages from the night before will be removed.

2. Your limb will be washed and thoroughly dried.

3. Your therapist will complete the manual lymphatic drainage (MLD) which is a very light massage that will remove or "drain" away the excess fluid in your limb. This massage also has to be completed the same order everyday. The massage will start in close to your body (sometimes on your neck) and move out towards your fingers or toes and then back in close to your body again.

4. While your therapist is massaging your limb, you will discuss the homework that you had from the night before.

5. After the massage, your therapist will teach you about bandaging your limb, massaging your limb, or other techniques to care for your limb.

6. Your limb will be bandaged with compression bandages to assist with decreasing the fluid in your limb.

7. You will be given a homework assignment for the next session.

8. Finally, there will be an opportunity for you to ask your therapist any further questions you may have that day.

When you get closer to the end of your therapy your therapist will help you decide on an appropriate compression garment for you to wear during the day and possibly another for night-time use. Your therapist will also help you to obtain these items.

Goals

During the course of your therapy, it is important that you develop personal goals that you and your therapist will work toward achieving. At the end of your first day, or "evaluation", your therapist will want to discuss these goals with you. It is OK to ask questions and to tell the therapist anything that you feel would help to make sure these goals reflect your unique situation.

Here is a sample goal to get you started: I will learn how to make changes to my daily schedule to make sure I have time to massage my arm.

Write your goals here, so you can look back at them to see how you are doing:

Goal #1_____

_____

_____

Goal #2_____

_____

_____

Goal #3_____

_____

_____

Goal #4_____

_____

_____

Goal #5_____

_____

_____

Goal #6_____

_____

_____

Goal #7_____

_____

_____

Treatment Organizer

Recording your treatment schedule here will help you remember when your next appointment is and what you need to do to meet your goals.

Week 1: _____						
Monday:	Tuesday:	Wednesday:	Thursday:	Friday:	Saturday:	Sunday:
Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:
Week 2: _____						
Monday:	Tuesday:	Wednesday:	Thursday:	Friday:	Saturday:	Sunday:
Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:

Treatment Organizer

Recording your treatment schedule here will help you remember when your next appointment is and what you need to do to meet your goals.

Week 3: _____						
Monday:	Tuesday:	Wednesday:	Thursday:	Friday:	Saturday:	Sunday:
Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:
Week 4: _____						
Monday:	Tuesday:	Wednesday:	Thursday:	Friday:	Saturday:	Sunday:
Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:	Appt: Homework: Page:

Chapter IV

Your Homework Activities

Homework activities can be helpful in examining how you feel and how you are coping with your diagnosis. The homework activities provided in this workbook are designed to be directed by your therapist and correspond to concerns addressed in treatment.

The activities are divided into two chapters. Chapter IV contains activities designed to help you develop your plan to manage lymphedema by making an adaptational response. These activities are meant to be completed in the order that they appear in this book. Chapter V has additional activities that help you to develop coping skills that help to support the plan you develop in chapter IV. Chapter V can be personalized to your unique situation, so don't be alarmed if you are not asked to complete all of the activities during the course of your treatment.

It is a good idea to write down which assignment you are working on in the treatment organizer in the previous chapter.

The Challenge

(Part I)

You have been presented with a challenge- the challenge of managing your lymphedema. You didn't ask for it. Frankly, you'd probably rather not even consider it; however, your challenge still exists. You need to make a response to that challenge, but how do you go about making a response that allows you to still be the person you are and meet all of the expectations that surround you?

You may be surprised to know that making a response to a challenge is actually a whole process that people go through multiple times everyday, sometimes every hour. The first step in the process is to know yourself and all of the circumstances surrounding you.

Questions:

Let's start with the environment that surrounds you every day. In the table below, fill in as many of the activities that you do on a typical day of the week. Also include activities that you have done in the past but are currently finding difficult. Try to group them under the column title that they most seem to go with. For example: When you get up in the morning do you shower, shave/put on makeup, fix your hair, and get dressed? These are all self care activities. When you go to work, what kind of work do you do? (Work also entails work that you do around the home – laundry, house cleaning, meal preparation, mowing, etc.) What kinds of activities are involved in your work? Finally, what do you do for fun?

Self-Care	Work	Play/Leisure

The Challenge
(Part II)

Lifestyle Balance:
This term relates to the idea that, generally, people's lives are spread evenly among activities that can be classified as Work, Self-Care, or Leisure.

Look at your completed worksheet of the Self-Care, Work, and Leisure columns and answer the following questions:
Do you have approximately the same number of activities in each column?
Yes _____ No _____
Which column(s) has the greater number of activities?
Self Care _____ Work _____ Leisure _____
Do you think that you have balance among the aspects of Self-Care, Work, and Leisure in your daily life? If not, why?_____
_____
_____

Are you satisfied with the imbalance? Describe why or why not? _____
_____
_____

Cultural Aspects of Your Environment:
Cultural aspects of a person's environment not only include the activities that are related to ethnicity, but also to the unwritten rules that govern the environments you participate in. For example, your ethnicity might be Scandinavian, but you also have rules that surround you at your office job such as the coffee break that the entire office takes at 10:00 a.m. sharp.

What type of ethnic culture do you come from?_____
_____

Are there any special events that occur because of your culture?_____
_____
_____

What other types of cultures are around you? (i.e. at work, at home, etc)_____
_____
_____

Is there anything in your cultural background (ethnic or otherwise) that prevents you from managing your lymphedema? Explain: _____
_____
_____
_____
_____

The Challenge

(Part III)

Social Aspects of Your Environment:

This area encompasses your friends, family, acquaintances, and even people that stand in line with you at the grocery store. It includes any event that has other people involved.

What kind of social activities do you attend?_____

_____

_____

Do you have concerns that your lymphedema will affect your social activities? Why or why not:

_____

_____

_____

_____

Identify places other than with friends and family that you have social contact with people (i.e. grocery store, movie theater, restaurant)?_____

_____

_____

_____

Are you concerned that your lymphedem will interfere with interaction with people in these areas? Explain:_____

_____

_____

_____

Physical Aspects of Your Environment:

The physical aspects of your environment are everything that you can touch and feel. The bed you sleep in at night, the toothpaste you use in the morning, the desk you use at your job, the washing machine at home, and the cart at the grocery store are all physical aspects of your environment.

Now, think about all of the physical aspects of the tasks you do everyday (chairs, shower stalls, desks, shampoo bottles, golf clubs, etc). Are there any physical objects that present challenges? List them here: _____

_____

_____

_____

_____

_____

_____

Getting to Know Yourself

Now that you have looked at your surrounding environment, you need to take a look at yourself. You may be thinking, "I already know myself better than anybody." This is true, however, when a person is faced with a new occupational challenge, it is important to "check in" with yourself and see how things are going.

All people have three parts to themselves that encompass all of who we are as individuals. Those three parts are:

- Physical self – made up of the actual parts of your body such as your arms, heart, muscles, nerves, etc.
- Thinking self – made up of your ability to think and remember.
- Emotional self – made up of your feelings and emotions.

Addressing each area will ultimately help you to make a response to your lymphedema.

Questions:

How do you think you will need to use your physical self to manage your lymphedema?_____

If you have any concerns about your ability to use your physical self to manage your lymphedema, describe them here:_____

Are there other physical factors that would influence your ability to manage your lymphedema? Describe:_____

How do you think you will need to use your mind (thinking skills, memory, etc.) to manage your lymphedema?_____

If you have any concerns about your thinking self, memory, etc. to manage your lymphedema, describe them here:_____

Getting to Know Yourself

Continued

Lymphedema is a lifelong condition that often requires therapy and medical equipment that may not be covered by insurance. Are you comfortable with your ability to manage your lymphedema financially? Describe:_____

_____

_____

_____

Take a minute now to think about what your past experience is with long term-conditions.

Have you ever had a long-term condition? If so, describe your experience:_____

_____

_____

_____

_____

What has your previous experience with healthcare professionals been like?
Positive _____ Negative _____ Unsure _____
Summarize your thoughts about dealing with medical professionals:_____

_____

_____

_____

_____

Have you ever sought treatment for your lymphedema before? Yes _____ No _____
Did you accomplish the goals you set out to address? Yes _____ No _____
Summarize your thoughts about experiencing previous lymphedema treatment:_____

_____

_____

_____

_____

Has anyone ever given you advice on how to take care of your lymphedema?
Yes _____ No _____
Was the advice useful? Yes _____ No _____
Did you have an emotional reaction to the advice? Yes _____ No _____
Describe:_____

_____

_____

_____

Your therapist will discuss this information with you at your next session. The next exercises will look at the psychosocial part of yourself.

Emotions

The psychosocial part of your self is made up of emotions. Strong emotions after diagnosis of lymphedema are very common.

From the list below, circle any emotions that you may be feeling right now.

Aggressive	Alienated	Angry	Annoyed	Anxious	Apathetic	Bashful
Bored	Cautious	Confident	Confused	Curious	Depressed	Determined
Disappointed	Discouraged	Disgusted	Embarrassed	Enthusiastic	Envious	Ecstatic
Excited	Exhausted	Fearful	Frightened	Frustrated	Guilty	Happy
Helpless	Hopeful	Hostile	Humiliated	Hurt	Hysterical	Hopeless
Interested	Jealous	Lonely	Loved	Mad	Mischievous	Miserable
Negative	Optimistic	Pained	Paranoid	Peaceful	Proud	Puzzled
Regretful	Relieved	Sad	Satisfied	Shocked	Shy	Sorry
Stubborn	Sure	Surprised	Suspicious	Thoughtful	Undecided	Withdrawn

Of the emotions you circled above, which 3 are the strongest for you right now?

1. _____
2. _____
3. _____

Identify activities that have helped you manage your emotions in the past?_____

_____

_____

What is it about these activities that you find helpful?_____

_____

_____

_____

How do you think your environment (the people, physical objects, and places around you) contributes to the feelings you circled?_____

_____

_____

_____

Adapted from Emotions Worksheet in:
Korb, K.L., Azok, S.D., & Leutenberg, E.A (1989). *Life skills management I.* Beachwood, OH: Wellness Reproductions, Inc.

Coping with Strong Emotions

Occupational therapy has long held that engaging in activities, or occupations, can be used to impact the effects of disease and disability (AOTA, 2002, p 610). This impact holds true for a variety of conditions including lymphedema. In order to cope with your strong emotions, it can be important to review your activities and identify which ones could be helpful to you.

From the list below, circle all the activities that you enjoy or would like to try.

Talking with Friends	Reading a book or magazine	Journaling	Going for a walk outside	Making a meal for a friend
Taking a bubble bath	Eating out at a restaurant	Getting your hair/nails done	Working on a car	Mowing the lawn
Gardening	Walking on a treadmill	Working out (like at a gym)	Playing video games	Watching your favorite program
Riding Bicycle	Scream (in a safe place)	Playing with pets	Getting a massage	Going to a movie
Running	Scrapbook	Photography	Golf	Mini-Golf
Playing an organized sport	Going on a trip	Visiting with family	Taking a boat ride	Skiing (Water or Snow)
Going for a drive	Going out for coffee	Going to the library	Attending a support group	Shopping
Listening to music	Using relaxation techniques	Sitting quietly and reflecting	Getting a hug from someone close to you	Attending an exercise class
Attending a book club meeting	Hiking	Attending a class on a subject that interests you.	Doing art work	Reading/writing poetry
Praying	Attending religious services	Laughing	Completing a Cultural activity	Attending a cultural event

Are there other activities that you do or would like to do? Write those activities here:

1._____ 5._____

2._____ 6._____

3._____ 7._____

4._____ 8._____

Life Roles

Now that you have identified various aspects of your environment and your self, it is time to consider the impact of environment and self on daily role performance.

You have occupational roles that you take on in your daily life. Occupational roles can be related to the work you do such as farmer, secretary, social worker, mechanic, etc or they can be related to things you do at home: mom, dad, brother, sister, daughter, son, etc.

What are some of the occupational roles in your daily life?_____
_____
_____

Each of these roles has expectations associated with it. For example: a parent may be expected to pick the children up from school and make them supper, a farmer is expected to plant crops and harvest them, and an office worker is expected to be punctual and arrive at work on time. These expectations are called *environment-generated* because they are outside of you.

What are some of the *environment-generated* expectations in your life presently?

1._____ 5._____
2._____ 6._____
3._____ 7._____
4._____ 8._____

You also have expectations of yourself when you participate in your occupational roles. For example: a parent of small children may expect him/herself to be able to apply discipline appropriately, a farmer may expect himself to work 12 hour days all year round, and an office worker may expect high quality work of him/herself. These expectations are called *person-generated* because they are inside of you.

What are some of the *person-generated* expectations is your life presently?

1._____ 5._____
2._____ 6._____
3._____ 7._____
4._____ 8._____

After examining your occupational roles above, are there any that are causing you undo stress or anxiety? Yes _____ No _____
Explain:_____
_____

Examining the occupational roles in your life allows you to look at all of the circumstances surrounding you. These circumstances will affect your ability to adapt to the occupational challenge currently facing you – managing your lymphedema.

Using Your Energy Wisely

Shultz and Schkade(1992) state that there are two types of energy that are used every day to adapt to the changes going on around and inside of a person. These two types of energy are labeled primary and secondary.

Primary is the type of energy that you use when you are concentrating on the issue at hand. For example: you are given a math problem to work on. When you are sitting at your table, looking at the math problem and thinking only about that math problem, you are using primary energy.

Secondary energy is used when you walk away from the math problem and do the dishes, go outside with your kids, or generally think about something else. Your brain doesn't quit working on the math problem and a couple hours later, you find that you have the answer. It just comes to you. In this case, it was the secondary energy that solved the problem.

Primary energy is not as efficient at secondary energy; therefore, you actually use more energy when you use primary energy.

Questions:

Provide examples of where you used primary energy while learning about management of your lymphedema in this program:

1. _____
2. _____
3. _____

Similarly, provide examples of where you used secondary energy:

1. _____
2. _____
3. _____

What has been the impact of using primary and secondary energy in your program?

_____
_____
_____
_____

This theory states that we are all born with a certain amount of energy which we use to adapt to the ever changing circumstances around us and in us. This is not a small amount of energy but it does have limits. It is not unlike an energy efficient washing machine. The less energy it uses on every wash cycle, the more energy is available for use later. It makes sense for all of us to use that energy wisely so that it continues to be available to adapt to changes around and inside of each person.

What Does History Have To Do With Lymphedema?

Everybody has patterns of behaviors they use to respond to challenges and changes in their lives. Sometimes, these patterns are helpful and lead to success. Sometimes, these patterns are not so helpful and lead to frustration. Successful or not, these patterns of behavior make up your collection of ways to respond. When a new challenge approaches, you turn to this collection of behavior patterns for possible ways to face the challenge. In times where the behavioral response selected doesn't get you outcome you wanted, you may modify that response or develop an entirely new response. Thus, the collection of behavioral responses changes as individuals grow and learn.

There are three types of behavioral patterns used to face a challenge:

Existing: A pattern that you already had in your collection. These are coping skills or problem solving approaches that you use now and have used in the past.

Modified: A pattern already in your collection that needs to be changed slightly for you to respond successfully. For example, if taking a trip is one of your patterns, but you can't currently leave treatment to go on a trip, you could go on a day trip to a local area on a day off from treatment. This is essentially the same pattern, just modified slightly to adjust to your circumstances.

New: A pattern that you have never used before. It's not in your collection currently, but can be added. This includes the development of new coping skills or problem solving approaches that you haven't tried before.

Questions:

What type of patterns do you think you are currently using to cope with your lymphedema?
Existing _____ Modified _____ New _____

Describe some of the ways you have been coping while you are in treatment:_____
_____
_____
_____
_____
_____

Of these behavior patterns, could you modify any of them or develop new patterns to continue to help you cope with your lymphedema? Describe:_____
_____
_____
_____
_____
_____

Rocks, Hamsters, and Trains

Have you ever been faced with a problem or challenge and the only thing you could do is just sit like a rock and stare at it? Or have you ever been like a hamster on a wheel running and running but never really addressing the problem? It's OK if you have. These are called adaptive response behaviors and they are ways in which we behave when faced with a challenge.

There are three kinds of adaptive response behaviors.

Primitive: This behavior presents as being like a rock: staring into space, unable to move past a block.

Transitional: This behavior presents as being highly mobile or moving from activity to activity without getting much done. This is like the hamster running on the wheel, lots of activity, but never addressing the goal.

Mature: This behavior presents as being like a train: heading straight for a goal in a logical fashion. When a person is able to approach a challenge with this behavior, he/she is able to get more done.

All three are normal responses at any given time, however, the mature response is one that will get the most done and move you closer to your goal.

Questions:

Right now, in regards to your lymphedema treatment, would you describe yourself as a rock, a hamster, or a train?

Rock _____ Hamster _____ Train _____

Is this behavior helping your accomplish the goals you identified on page 15? Why or why not?

_____

_____

_____

_____

Are you satisfied with this behavior? Why or why not?_____

_____

_____

Which behavior would help you to accomplish those goals?

Rock _____ Hamster _____ Train _____

What could you do to start using the behavior you just identified?_____

_____

_____

_____

Making a Plan

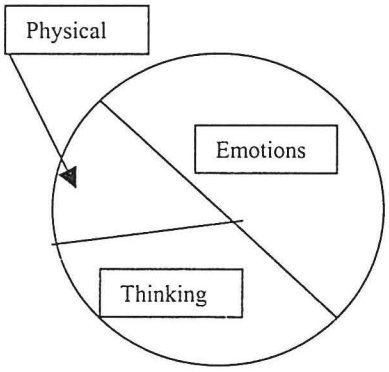
To begin to formulate a plan for caring for your lymphedema, it is important to look at what parts of yourself you need to use most. Remember, there are three parts to you:

Thinking self (memory, problem solving, etc)

Emotional self (feelings)

Physical self (actual parts of your body – arms, legs, hands, etc.)

When you confront a challenge in your life, you need to use different amounts of yourself to be successful with that challenge. For example, if the challenge is to deal with the death of a parent, your use of self may look like this:



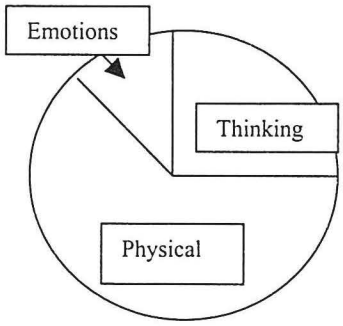
In this situation:

*You would need to draw heavily on your **emotional** self to deal with your grief.

*You would need your **thinking skills** to help plan the funeral but probably in a smaller amount than your emotions.

*Finally, you would need to use your **physical** self to walk to the places you would need to go, but, again, less than the other parts of your self.

If the challenge is to learn how to water ski, your use of self might look like this:



In this situation:

*You need the **physical** part of yourself more because water skiing requires you to use your body to be successful.

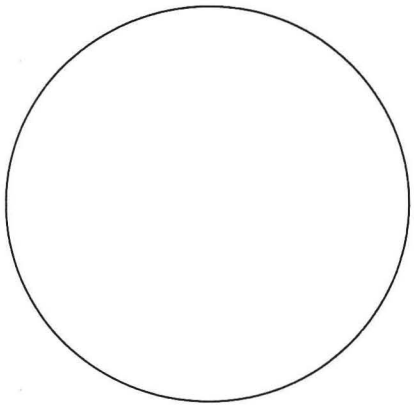
*You need your **thinking skills** to problem solve what works and what doesn't and to remember what you were taught.

*Finally, your **emotions** come into play because you may be nervous or afraid.

Complete the questions on the next page:

Making a Plan Continued

Questions:
How would you depict your use of self (physical, thinking, and emotional) as you go about managing your lymphdema? Complete the circle below.



Take a minute to reflect on your circle.

Do you need to use one part of yourself more than the others? Why?_____
_____
_____
_____
_____

What part of yourself do you need to use most?
Thinking self _____ Emotional self _____ Physical self _____

In your opinion, is it difficult to use the part of yourself that you identified above? Explain:_____
_____
_____
_____
_____
_____
_____

What could you do to learn to use the part you identified in a more effective manner?_____
_____
_____
_____

What could you do to use the other parts of yourself in a more effective or efficient manner?_____
_____
_____
_____

Items I Need for My Plan to Manage Lymphedema

Fill in the sections below with the items you think you will need to manage your lymphedema:

Supplies:

Space:

Written Materials:

Other items:

Fill in the sections below with the skills you think you will need to manage your lymphedema:

Combined Decongestive Therapy Skills: i.e. bandaging, massage, etc

Coping Skills:

Other:

A Typical Day in My Plan to Manage Lymphedema

When making your plan to manage your lymphedema, it is important to try it out in a sample of what a typical day might look like for you. Think of this as a snapshot of your plan.

In the blank schedule below, write in what a typical day's plan might be for you. You will want to include typical activities for you: going to work, doing house work, meals, etc. (refer to page BLANK). Be sure to include all your lymphedema care. If your typical times are not on the sheet, change the times to suit your schedule.

Time	Activity
6:00 a.m	
7:00 a.m.	
8:00 a.m.	
9:00 a.m.	
10:00 a.m.	
11:00 a.m.	
12:00 p.m.	
1:00 p.m.	
2:00 p.m.	
3:00 p.m.	
4:00 p.m.	
5:00 p.m.	
6:00 p.m.	
7:00 p.m.	
8:00 p.m.	
9:00 p.m.	
10:00 p.m.	
11:00 p.m.	

A Typical Week in My Plan to Manage Lymphedema

Now that you've tried out a daily schedule, try to expand it to a typical week.

In the blank schedule below, write in what a typical week's plan might be for you. Again, put in as many typical weekly activities as you can. Also, be sure to include all your lymphedema care. Start your schedule on this page and continue it on the next page. If your typical times don't fit this grid, change the times to suit your schedule.

Time	Monday Schedule	Tuesday Schedule	Wednesday Schedule	Thursday Schedule	Friday Schedule	Saturday Schedule	Sunday Schedule
5:00 a.m.							
6:00 a.m.							
7:00 a.m.							
8:00 a.m.							
9:00 a.m.							
10:00 a.m.							
11:00 a.m.							
12:00 a.m.							
1:00 p.m.							
2:00 p.m.							

A Typical Week in My Plan to Manage Lymphedema

This schedule is a continuation of the previous page where you began your typical week.

Fill in the schedule in the same manner as the previous page. Put in as many typical weekly activities as you can. Also, be sure to include all your lymphedema care. Remember, if your typical times don't fit this grid; change the times to suit your schedule.

Time	Monday Schedule	Tuesday Schedule	Wednesday Schedule	Thursday Schedule	Friday Schedule	Saturday Schedule	Sunday Schedule
3:00 p.m.							
4:00 p.m.							
5:00 p.m.							
6:00 p.m.							
7:00 p.m.							
8:00 p.m.							
9:00 p.m.							
10:00 p.m.							
11:00 p.m.							
12:00 p.m.							

A Typical Special Occasion in My Plan to Manage Lymphedema

Now that you've tried out daily and weekly schedules, it is important to think about what you will do on special occasions. Special occasions can be any event or holiday that is special to you: Christmas, weddings, parties, etc. You may find on these days that your plan needs to be adjusted somewhat to accommodate the change in daily schedule that often comes at these times.

Fill in the schedule below. Be sure to include typical daily activities, activities unique to the special occasion, and any lymphedema management that you will need to complete.

Time	2 Days Before	1 Day Before	Special Occasion Schedule	1 Day After	2 Days After
6:00 a.m.					
7:00 a.m.					
8:00 a.m.					
9:00 a.m.					
10:00 a.m.					
11:00 a.m.					
12:00 p.m.					
1:00 p.m.					
2:00 p.m.					
3:00 p.m.					
4:00 p.m.					
5:00 p.m.					
6:00 p.m.					
7:00 p.m.					
8:00 p.m.					
9:00 p.m.					
10:00 p.m.					
11:00 p.m.					

Chapter V

Additional Worksheets

Congratulations! You have developed a plan to manage your lymphedema. It was probably hard work and you should be proud of yourself. The following worksheets address coping skills that may be helpful to you while trying to follow your plan. These skills can become part of your collection of behavioral responses to challenge and be available to you whenever you need them.

Talking to Other People About My Lymphedema: Communication Skills

It's unavoidable. You will be walking along the street and someone will say to you, "What happened to your arm?" Or maybe you'll be spending the day at the beach with friends and someone says "What's wrong with your leg?" No matter how hard you try to hide it, the public (including friends and family) will always be curious about your lymphedema. Even though it may feel hurtful, most people are just curious. But how do you respond to questions like this?

Depending on your personality and your comfort level, there are several options:

- Respond with **actual facts**: you can explain exactly what lymphedema is, why you have it, and how it affects you – or any combination of these topics.

- Respond with **humor**: you can make something up. "I fell off an elephant that I was riding at those rides at the circus." Or maybe, "It was supposed to be flag football, but we got a little carried away!" Be creative.

- Respond in a **short and to-the-point** manner: "I have lymphedema and it makes my (arm or leg) swell." Moving on to another subject after this statement may also help to divert attention away from your limb and on to other topics of mutual interest.

You may find that you use different responses for different people. You may tell a stranger on the street that you fell off a ladder while you tell a family member exactly what is going on with you. Each response will depend on how you feel about the person you are talking too. Use the response that works best for you.

Questions: What is your comfort level with each response? Mark where you fall on each of the lines below:

Actual Facts

Comfortable_____Uncomfortable

Humor

Comfortable_____Uncomfortable

Short and To-the-Point

Comfortable_____Uncomfortable

Write examples of each of the three types of responses here:

1. Actual Facts:_____

_____

2. Humor:_____

_____

3. Short and To-the-Point:_____

_____

What's So Special About Me?
Self-Concept Strengthening

Lymphedema can have a profound effect on an individual's self-concept. Self-concept includes how you feel about yourself, if you like or dislike yourself, self-confidence, self-image, and self-esteem. When self-concept is low because of lymphedema, you may feel as though there is something "wrong" with you. You may feel that your body is somehow less appealing than it was before. You may lack confidence in yourself when attempting activities. You may also have other negative thoughts about yourself.

At times when your self-concept is low, it is important to replace the negative thoughts you have with positive ones. There are several techniques for this:

- Identify the negative thoughts you are having and replace them with positive ones.
- Say "STOP" to yourself whenever you catch yourself thinking negative thoughts about yourself and then think about something else.
- Use the coping skills that you identified earlier in this workbook.

Using these techniques will help you to remain positive and boost your self-concept.

Questions: Talking negatively to yourself can cause a decrease in your self-concept. In the left column below write down some of the negative things you say to yourself about your swollen limb. After you finish, try changing the negatives into positives and write them in the right column. An example has been provided.

Negative Thought	Positive Thought Change

Look back at your list of activities to deal with strong emotions on page 25. Using some of those activities will help to decrease your negative thoughts.

Am I Up to This Challenge?
Self-Confidence Strengthening

Self-confidence is a part of your self-concept. Having confidence in your ability to manage your lymphedema is an important part of successfully caring for your lymphedema. During the course of this treatment program, you have been learning many skills and techniques to manage your lymphedema. This information is helpful but can also be overwhelming. As a result, your self-confidence in your ability to manage your lymphedema may be low. In order to increase your self-confidence, it is helpful to list out all of the positive things you can do to manage your lymphedema.

Questions: In the left column of the table below, list out the skills you have learned in treatment to manage your lymphedema. Then think about how each skill will allow you to manage your lymphedema more effectively. Write those ideas in the right column.

Skill	How Does this Skill Help Me
Example: Bandaging	By being able to bandage my own limb, I will be able to control my lymphedema by wrapping when I need extra compression.

Look back at your list of activities to deal with strong emotions on page 25. Using some of those activities will help to increase your feelings of self-confidence.

REMEMBER: Everyone is special in his/her own way. You are no different. **Lymphedema can't change the person you are inside unless you let it.**

You Don't Paddle a Canoe by Yourself: Current Support Systems

Just like you don't paddle a canoe by yourself and you don't climb a mountain alone, you don't manage your lymphedema alone either. Yes, you *can* paddle a canoe on your own. Yes, you *can* climb a mountain on your own, but the work is much harder and you may not be as successful. It is the same with management of your lymphedema.

When you are coping with all of the demands that have been placed on you, it is a good idea to identify your support system. Your support system consists of the people around you that support you. They could be friends, family, medical professionals, clergy, or support group members. They may show their support in different ways: giving you the information you need, helping wrap your arm, or just being the listening ear that you need. The one thing they all have in common is that they are supportive of you.

Questions:

My Current Supports: In the chart below, write in the names of the people who support you, how to contact them, and what type of support they can give you. If you need more space, use another piece of paper and staple it to this sheet so you can find it.

Support Person	Contact Number(s)	Type of Support Given

What If There Aren't Enough People in My Canoe? Developing New Support Systems

As we grow and change, our support systems change too. People we are used to relying on may not be available to us. Because of this, it is sometimes necessary to add people to an already established support system or develop a new system altogether.

There are many ways to add to an existing or develop a new support system. For example: joining a support group, volunteering, attending activites at a religious institution, and attending community activities are all ways to meet new people who could potentially be added to your support system.

Questions:

Look back at the previous worksheet where you listed your supports. Are you satisfied with the number and types of supports you have? Why or why not: _____

_____

_____

What are some places or events in your community that where you could meet people?

1._____ 4._____

2._____ 5._____

3._____ 6._____

In order to start developing a plan to either add to your support system or to develop a new support system, it is important to write down what you want to accomplish in the form of a goal. In order to be effective, goals often need to be followed with action. In the grid below, write in what your goals and what action you will take to meet those goals. An example is provided.

Goal	Action Statement
I want to develop a new support in the community.	I will volunteer at the local hospital.

Keeping Your Focus: Spirituality

When considering your support system, it is important to remember to include your spirituality. Spirituality resides in you, shapes the world around you, and gives meaning to the things you do everyday (Law, Polatajko, Baptiste, and Townsend, 1997). Spirituality can mean organized religious events and practices or it can mean activities that uplift your soul/spirit. It is the way the humans find meaning in life. Spirituality helps people cope with life events such as lymphedema. You have other people in the canoe with you, but often times spirituality is your life preserver.

Questions:

From the list below, identify activities that make you feel uplifted, calm, in touch with yourself, or motivated to accomplish goals.

Reading	Music	Meditation	Gardening
Letter-writing	Painting	Creative Writing	Photography
Museums/Galleries	Experiencing Nature	Attending a religious service	Prayer
Silent reflection	Journaling	Cultural activities	Arts and crafts

Are there any activities that you do to make you feel uplifted, calm, in touch with yourself, or motivated to accomplish goals that are not listed above? Identify them here:_____

Being spiritually healthy can affect physical health and well-being. Are you spiritually healthy? Describe why or why not:_____

How can you use your spirituality to help you cope with your lymphedema?_____

A Lifetime is a Long Time: Commitment

Managing your lymphedema is a lifetime commitment and it can be a little overwhelming. Making a lifetime commitment to manage a disease means maintaining that level of commitment over time. In order to stay focused on managing your lymphedema, there are several things you can do:

- Take it day by day (or even hour by hour). Worrying about all the days to come is anxiety producing. Focusing on today, rather than all those days to come, will help to decrease that anxiety.

- If you start to feel overwhelmed, go back to your list of activities to deal with strong emotions. Engaging in these activities can also help to decrease feelings of anxiety and depression.

- Make sure you are using your support system. Refer back to the list you made previously and make plans to stay in contact with people who care about you.

Using these skills can help you to feel more in control of your lymphedema and less overwhelmed.

Questions:

How do you think you can maintain a commitment to manage your lymphedema?_____
_____
_____
_____
_____

How are you going to maintain an emotional balance that copes with anxiety, depression and other strong emotions?_____
_____
_____
_____
_____

How can you keep in contact with your support system?_____
_____
_____
_____
_____

Is there anything else you can do to maintain your commitment to manage your lymphedema?____
_____
_____
_____

Chapter VI

Evaluating Your Program

Now that you've developed your plan to manage your lymphedema, there is one final step for you to complete before you are discharged from formalized treatment. You need to check to see if your plan is really working for you. By looking at your plan through the next exercises, you will be able to determine if the plan will work for you or if it needs some adjustments to enable you to be successful.

Is My Plan Working for Me Now?

In order to determine if your plan is working for you, you need to consider the following:

- Is my plan efficient? Does it make good use of my time, energy, and resources?

- Is my plan effective? Am I keeping my lymphedema under control while still completing the everyday activities I want to do?

- Am I satisfied with my plan? Is the society around me satisfied with my plan? Am I satisfied with the outcome? Is the society around me satisfied with the outcome?

*Note: The society around you includes friends, family, work expectations either inside or outside of the home, etc.

Let's look at an example of this. Imagine for a moment that your management plan includes night bandaging of your limb. You bandage every night; it takes you an hour to get all the bandages on the right way so you need to get ready for bed much sooner than the rest of your family. Even though it takes you a long time, you are able to get the bandages on and as a result, the swelling in your limb is decreased. Imagine also that you work as a secretary and because your lymphedema is controlled, you are able to go to work and complete all the tasks that are assigned to you. Your employer is very happy with your performance and he compliments you by saying "I couldn't run this place without you." If you consider this scenario with the above questions, your outcome may look like this:

- **Efficiency**: This plan is not very efficient because it takes an hour to wrap your limb every night.

- **Effectiveness**: This plan is effective because your lymphedema is well controlled and you can complete your work activities.

- **Satisfaction of self/society**: This plan is not very satisfying to you because it takes you an hour to wrap your limb and takes you away from family activities. It is satisfying to society (your employer) because you are able to get your work done and you received a compliment.

With the example above, you would need to look at the efficiency of putting bandages on at night. If this is not satisfactory to you, you would need to look for a way to be more efficient. You might talk to your therapist who would recommend a night-time garment that was easier to put on. You make this change and after 3 months you evaluate your plan again and this time you find:

- **Efficiency**: This plan is very efficient because now it only takes 10 minutes to don your night-time garment.

- **Effectiveness:** This plan is still effective because your lymphedema is well controlled and you are still able to complete your work activities.

- **Satisfaction of self/society**: This plan is now satisfying to yourself because it takes you less time to put on your night-time garment and you have more time for your family. It is satisfying to society (your employer) because you are still able to get your work done and you even received another compliment.

With these three ideas, use the next pages to check your plan.

Is My Plan Working for Me Now?

Use the three ideas of efficiency, effectiveness, and satisfaction to self/society to look at your own plan and see if it is working for you.

Questions:

What parts of your plan are efficient?

What parts of your plan could be more efficient?

What parts of your plan are effective?

What parts of your plan could be more effective?

With which parts of your plan are you satisfied?

With which parts of your plan are you less satisfied?

What parts of your plan are satisfying to the society around you?_____

What parts of your plan are less satisfying to the society around you?_____

What changes could you make to your plan to address the items you listed above as not being efficient, effective or satisfying to self/society?

Improvements to Efficiency:_____

Improvements to Effectiveness:_____

Improvements to Society Satisfaction:_____

How Has Your Plan Changed You?

Making a change in response to a challenge can have an effect on you. That effect usually comes about after you stop to reflect on the process of making the change in the first place. Now is a good time to reflect on the process you went through to make your plan to manage your lymphedema.

Questions:

How do you feel about the plan you made?_____

After reviewing your plan for efficiency, effectiveness, and satisfaction, do you have any other feelings about your plan?_____

Are you now able to make decisions about how to do other daily tasks while still managing your lymphedema? Explain:_____

Describe any changes you've made that weren't specifically suggested by your therapist?_____

Think back to how you felt about your lymphedema before you began treatment. How have your feelings changed since you developed your plan? _____

How Has Your Plan Changed Your Environment?

Your environment is made up of the physical objects that surround you, the social groups that you participate in, and the cultures that affect you. Cultures can be your hereditary culture (Swedish, Native American, etc) or they can be the culture of the places you go everyday (workplace, religious institution, etc). Your environment does not sit on the sidelines while you are putting together a plan. Exactly the opposite, the environment plays a role by having expectations of you. Once you put your plan in place, your plan actually has an effect on your environment. Take a moment to reflect on how your plan to manage lymphedema has affected your environment.

Questions: While reflecting on the plan you developed, answer the following questions:

Describe what has changed in your physical environment. Include any new physical items that have been added or changed:

Describe any changes to your social groups (refer to page 21):

Describe any changes to either your ethnic culture or to other cultures that surround you as a result of your plan (refer to page 20):

If you haven't already, how could you incorporate these changes into your plan?

Chapter VII

Checking In With Your Plan

In the future, it is a good idea to check in with your plan periodically to make sure it is still working for you. The time span may differ for different people, but in general, it is a good idea to check in with your plan whenever you experience a change to yourself or your environment. That way, you can be sure it is working for you.

The old adage the only thing that is certain in life is change, applies to your plan to manage lymphedema too. Your personal circumstances will change. Your environment will change. Your support system will change. By checking in with your plan, you will be able to see how to make changes that will allow you to continue caring for your lymphedema...and yourself.

The following exercises should be completed several times in the future. It is recommended that you complete these exercises 1-2 months after discharge from your lymphedema program and then periodically after that. These exercises are designed to assist you in determining what, if any, changes need to be made to your program. During this process, you may find that you have questions or concerns. If you do, make sure to contact your therapist so that he/she can assist you as necessary.

You may need to make copies of these exercises so that you can use them again in the future.

Is My Plan Working for Me Now?

Use the three ideas of efficiency, effectiveness, and satisfaction to self/society to look at your own plan and see if it is working for you. Refer to page 46 for definitions.

Questions:

What parts of your plan are efficient?

What parts of your plan could be more efficient?

What parts of your plan are effective?

What parts of your plan could be more effective?

With which parts of your plan are you satisfied?

With which parts of your plan are you less satisfied with?

What parts of your plan are satisfying to the society around you?_____

What parts of your plan are less satisfying to the society around you?_____

What changes could you make to your plan to address the items you listed above as not being efficient, effective or satisfying to self/society?

Improvements to Efficiency:_____

Improvements to Effectiveness:_____

Improvements to Society Satisfaction:_____

Items I Need for My New Plan to Manage Lymphedema

Now that you have identified the changes you need to make to your plan, check to make sure that you still have all the items and skills that you need to be successful

Items:

Supplies:

Space:

Written Materials:

Other items:

Skills:

Combined Decongestive Therapy Skills: i.e. bandaging, massage, etc

Coping Skills:

Other:

A Typical Day in My New Plan to Manage Lymphedema

Now that you have decided on some changes to your plan, try them out on the schedule below.

In the blank schedule below, write in your new typical day's plan. You still want to include typical activities for you: going to work, doing house work, meals, etc. Be sure to include all your lymphedema care. If your typical times are not on the sheet, change the times to suit your schedule.

Time	Activity
6:00 a.m.	
7:00 a.m.	
8:00 a.m.	
9:00 a.m.	
10:00 a.m.	
11:00 a.m.	
12:00 p.m.	
1:00 p.m.	
2:00 p.m.	
3:00 p.m.	
4:00 p.m.	
5:00 p.m.	
6:00 p.m.	
7:00 p.m.	
8:00 p.m.	
9:00 p.m.	
10:00 p.m.	
11:00 p.m.	

A Typical Week in My New Plan to Manage Lymphedema

Now that you've tried out a new daily schedule, try to expand it to a typical week.

In the blank schedule below, write in the new typical week's plan. Again, put in as many typical weekly activities as you can. Also, be sure to include all your lymphedema care. Start your schedule on this page and continue it on the next page. If your typical times don't fit this grid, change the times to suit your schedule.

Time	Monday Schedule	Tuesday Schedule	Wednesday Schedule	Thursday Schedule	Friday Schedule	Saturday Schedule	Sunday Schedule
5:00 a.m.							
6:00 a.m.							
7:00 a.m.							
8:00 a.m.							
9:00 a.m.							
10:00 a.m.							
11:00 a.m.							
12:00 a.m.							
1:00 p.m.							
2:00 p.m.							

A Typical Week in My Plan to Manage Lymphedema

This schedule is a continuation of the previous page where you began your typical week.

Fill in the schedule in the same manner as the previous page. Put in as many typical weekly activities as you can. Also, be sure to include all your lymphedema care. Remember, if your typical times don't fit this grid; change the times to suit your schedule.

Time	Monday Schedule	Tuesday Schedule	Wednesday Schedule	Thursday Schedule	Friday Schedule	Saturday Schedule	Sunday Schedule
3:00 p.m.							
4:00 p.m.							
5:00 p.m.							
6:00 p.m.							
7:00 p.m.							
8:00 p.m.							
9:00 p.m.							
10:00 p.m.							
11:00 p.m.							
12:00 a.m.							

A Typical Special Occasion in My New Plan to Manage Lymphedema

Finally, try out your new plan for special occasions. Remember, special occasions can be any event or holiday that is special to you: Christmas, weddings, parties, etc.

In the blank schedule below, write in what your next holiday/special occasion will look like with the new plan. Be sure to include the 2 days just before and the 2 day just after. Be sure to include any changes you may have made from your first schedule:

Time	2 Days Before	1 Day Before	Special Occasion Schedule	1 Day After	2 Days After
6:00 a.m.					
7:00 a.m.					
8:00 a.m.					
9:00 a.m.					
10:00 a.m.					
11:00 a.m.					
12:00 p.m.					
1:00 p.m.					
2:00 p.m.					
3:00 p.m.					
4:00 p.m.					
5:00 p.m.					
6:00 p.m.					
7:00 p.m.					
8:00 p.m.					
9:00 p.m.					
10:00 p.m.					
11:00 p.m.					

Chapter VIII

Other Resources You May Find Helpful

You have now been through the occupational adaptation process of making a plan to take care of your lymphedema. Science is making fast paced changes in regard to lymphedema. Because of this, you may be interesting in keeping up to date or simply supplementing what you have learned here.

For more information:

Coping with Lymphedema:

Burt, J., & White, G. (1999). *Lymphedema: A breast cancer patient's guide to prevention and healing*. Alameda, CA: Hunter House, Inc.

An easy to read resource that explains breast cancer related lymphedema and treatment. Testimonials from patients and information on coping are included.

McMahon, E. (2005).*Overcoming the emotional challenges of lymphedema*. San Francisco, CA: Lymph Notes.

Presented in a workbook style format, this book provides an in-depth look at the different types of emotions that can surface with lymphedema. Activities to address coping are included.

Swirsky, J., & Sackett Nannery, D. (1998). *Coping with lymphedema*. New York, NY: Penguin Putnam, Inc.

This text gives an overview of lymphedema and treatment options. It also discusses lifestyle changes and coping with yourself and others.

Lymphedema Websites:

The National Lymphedema Network. www.lymphnet.org

The National Lymphedema Network is an internationally recognized non-profit organization based in the United States which provides education about lymphedema. This site includes education about lymphedema, support group listings, pen pals, advocacy, information on clinical trials, and patient summits. There is also a list of therapists who are members of the organization and has a web based book store.

Lymphology Association of North America. www.clt-lana.org

LANA is a non-profit corporation composed of healthcare professionals experienced in the field of lymphology and lymphedema. This group is based in North America and promotes testing and certification of medical professionals who treat lymphedema. A list of LANA certified lymphedema therapists and the standards for certification are provided.

Lymphovenous Canada. www.lymphovenous-canada.ca

This is a Canadian based website that links patients, health care professionals, and support groups. This website provides information on new studies and topics of interest to patients with lymphedema.

Lymphoedema Association of Austrailia. www.lymphoedema.org.au

This Austrailian based website contains a summary of information about lymphedema, its causes, treatment and related matters.

Lymphoedema Support Network. www.lymphoedema.org

Based in the United Kingdom, this website provides an overview of lymphedema and related matters.

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CHAPTER V

SUMMARY

Lymphedema is an accumulation of protein rich fluid in the body's tissues caused by dysfunction of the lymphatic system. People diagnosed with lymphedema are at risk for physical limitations such as decreased range of motion, decreased strength, pain, neurological deficits, and decreased flexibility. In addition to this functional morbidity, people diagnosed with lymphedema have higher levels of psychological, social, and sexual morbidity. The lived experience of persons with lymphedema indicates that this group experiences disruption in everyday activities. Overall, the literature reflects that lymphedema has adverse effects on the client factors of body functions and body structures including: the emotional self, experience of self and time, sensory and pain, neuromusculoskeletal, and movement-related functions as defined by the occupational therapy practice framework (AOTA, 2002). These adverse effects subsequently affect performance skills, performance patterns, and ultimately performance in areas of occupation as outlined in the occupational therapy practice framework (AOTA, 2002).

Currently, there is no cure for lymphedema and the overall preferred method for treatment is combined decongestive therapy (CDT). CDT is a conservative treatment consisting of a specific type of massage (manual lymphatic drainage or MLD), compression bandaging, specific exercises, skin care techniques, preventative recommendations, and use of compression garments for day and night wear. In order to

treat lymphedema with CDT an occupational therapist, occupational therapy assistant, physical therapist, physical therapy assistant, massage therapist, nurse, or physician must attend further training outside of his or her professional training. Episodes of treatment have been shortened by third party payers and certain educational activities are no longer reimbursed at all through the Medicare program. Reduction is no longer the focus of treatment; rather, the focus is assisting the patient to become independent with self-management of lymphdema. Often times, patients are taught the occupational readiness skills to manage the lymphedema, but are not assisted in making the adaptational response necessary for long-term management. A workbook for patients with lymphedema based upon the occupational adaptation theoretical frame of reference is necessary to assist the patient in making the necessary adaptational response.

Occupational therapists are uniquely qualified to address this shortcoming by utilizing their knowledge of the use of occupation to make an adaptational response. The theory of occupational adaptation holistically addresses this issue. The workbook is used as homework with discussion and therapeutic instruction incorporated into CDT concurrently with the 30-45 minutes necessary for the manual lymphatic drainage portion. The workbook could also be used consecutively within the process of CDT in countries or with insurance plans that would allow this type of treatment. This workbook in this scholarly project is designed for established lymphedema clinics where the treating therapist is knowledgeable in CDT and occupational adaptation principals.

Limitations

There is no implementation data to support the use of this workbook to promote occupational adaptation process in a population of patients receiving treatment for

lymphedema. Further research could address this issue. Implementation of the workbook through several different clinics to determine if changes need to be made to the exercises based on demographic populations and regional differences is necessary. Research on the outcomes of treatment could be measured by a standardized occupational therapy assessment such as the Assessment of Motor and Process Skills to provide information as to the efficacy of this product. A second limitation is that this workbook needs to be implemented by a clinician skilled in both the use of occupational adaptation theoretical frame of reference and CDT. The occupational therapist with limited knowledge regarding the frame of reference would need to further explore the occupational adaptation theoretical frame of reference to be competent in implementation.

Proposal for Implementation

This workbook is suitable for integration into an established lymphedema management program within an occupational therapy department. The treating occupational therapist begins with an evaluation as outlined in this scholarly project. He/she establishs a plan in conjunction with the patient to treat the lymphedema. The therapist introduces the workbook and assigns worksheets as homework. On the next treatment day, the therapist reviews the assigned worksheet concurrently with the manual lymphatic drainage portion of the treatment session. Therapy continues until the patient had successfully reduced his/her lymphedema to the point where it can be managed through a home program, which is established by the joint efforts of the patient and the therapist while utilizing the workbook. Upon completion of the treatment program, the patient is discharged with instructions to evaluate his/her management plan periodically and to contact the therapist if he/she has any questions or concerns. In areas where

insurance or facilities allow, this workbook could also be used consecutively with CDT treatment.

Conclusions

Occupational therapy is uniquely able to address the need for occupational adaptation within this population. In contrast to other professions treating this population, occupational therapists have extensive education regarding engagement in occupation to support participation in context as defined by the occupational therapy practice framework (AOTA, 2002). It is this understanding of occupation, life roles, and the steps required to make a positive adaptational response that qualifies occupational therapists to assist this population to not only develop a plan to manage lymphedema, but also integrate that plan into daily occupational activities. Occupational therapy is also uniquely situated to educate other professions treating this population about the importance of the use of occupation to treat patients with lymphedema. In order to holistically address long term management of lymphedema, occupational therapy should educate the lymphatic community regarding the importance of engagement in occupation with this population to not only control the size of lymphedema, but also to improve positive coping through the use of occupation. It is recommended that further research be completed in this area to address the role of occupation in the long term management of and coping with lymphedema.

APPENDICES

Appendix A

An Example of Occupational Adaptation in Action

An Example of Occupational Adaptation in Action

In the occupational adaptation theoretical frame of reference, occupational challenges arise from the interaction that occurs between the person's desire for mastery and the occupational environment's demand for mastery. This occupational challenge is influenced by the occupational environments (work, play/leisure, and self-care) surrounding it and also the occupational environment subsystems (physical, social, and cultural). The occupational challenge is also influenced by the person systems (sensorimotor, cognitive, and psychosocial) and subsystems (genetic, environmental, and phenomenological). Occupational role expectations also need to be assessed in order to have a holistic approach to the occupational challenge. For example, consider Byron who is a college student writing a term paper. Byron has an internal desire to write an A paper to maintain his good grade point average. His teacher also has an expectation that he will complete the paper and turn it in on time. This internal desire and external demand create a press for mastery and subsequently an occupational challenge. The occupational environment for Byron would be work and this environment has several expectations that are outside or external to him. The desk that he sits at, the lighting from his desk lamp, and the set up of his computer will have an effect on the occupational challenge (physical subsystem). The people around Byron such as his roommate, other people on the floor of his dorm, and the classmates that periodically call him for help on their papers also need to be considered (social subsystem). Byron is surrounded by the culture of the university which demands that he attend class, complete his homework assignments and turn them in on time (cultural subsystem). The occupational challenge of writing a term paper will be affected by Byron's own internal expectations and abilities. His hand coordination for

typing, ability to maintain his posture while typing, and his ability to see the computer screen (sensorimotor system) will affect how successful he is at writing his paper. Also playing a role is Byron's ability to recall information that he has researched at the library and process that information into a term paper format (cognitive system). Byron may also have a small amount of anxiety about completing the paper as it is a large part of his grade for the course (psychosocial system). Looking deeper into his own expectations, one would find that he has the physical stature and coordination necessary to use a keyboard (genetic subsystem). He also is on scholarship and must keep his grades up in order to maintain his financial funding for school (environmental subsystem). Finally, Byron has written many term papers in the past and has had good success (phenomenological subsystem). All of these factors will influence Byron's occupational role expectations which in turn will influence his approach to the occupational challenge of completing his term paper.

Once all of the factors of person, environment, and occupational role expectations are considered, the person will access the adaptive response generation sub-process which consists of the adaptive response mechanism (adaptation energy, adaptive response modes, and adaptive response behaviors) and the adaptation gestalt (psychosocial, sensorimotor, and cognitive). The adaptation energy is split into two sub-categories: primary energy and secondary energy. The adaptive response modes are divided into three sub-categories: existing, modified, and new. The adaptive response behaviors are divided into three sub-categories: primitive, transitional, and mature.

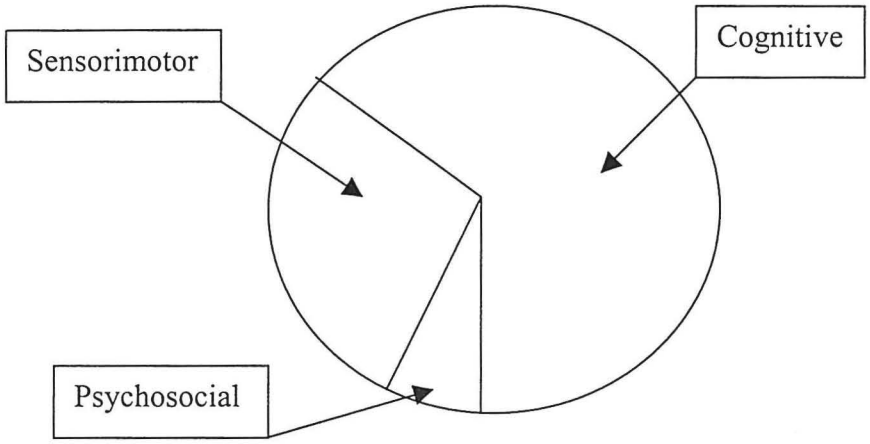
Once again, consider Byron, the student with the term paper. As he begins to write his term paper, he goes to the library to look up applicable references. While he is

doing this he is using primary energy because he is focused only on the topic for his paper. After several hours, he takes a break to eat some supper, catch up with some friends, and watch a little television. During this time, he is still processing the problem of how to write his paper through the use of secondary energy. Secondary energy is more efficient, and later on when he sits down to write the paper he finds that it is easier to start. At the same time, he is using an existing response mode because in the past he has always started his papers at the library. Since that mode has worked well for him in the past, he will continue to use it. If, for some reason, this mode did not work for him this time, he may choose to use a modified mode such as using a different search engine at the library computer or using the completely new mode of looking up information on the internet at his dorm room. Finally, Byron displays specific adaptive response behaviors while writing his paper. Byron may find that after he starts his paper as noted above, he comes to a section that isn't working for him. In response, he sits and stares at the computer screen or at the ceiling and does absolutely nothing. This is the primitive response behavior. After a while, he gets up and starts cleaning his dorm room. He organizes his desk and even cleans the toilet. He wanders up and down the halls, not really accomplishing anything. This is the transitional response behavior. After several hours of this, Byron is able to sit back down at the computer and get past the section he was having trouble with. This is the mature response behavior.

Byron also needs to formulate an adaptation gestalt. To write his term paper, he has to use a large amount of his cognitive abilities to formulate the paper. He also uses his sensorimotor abilities, however, not to the same extent. Finally, since he his a little

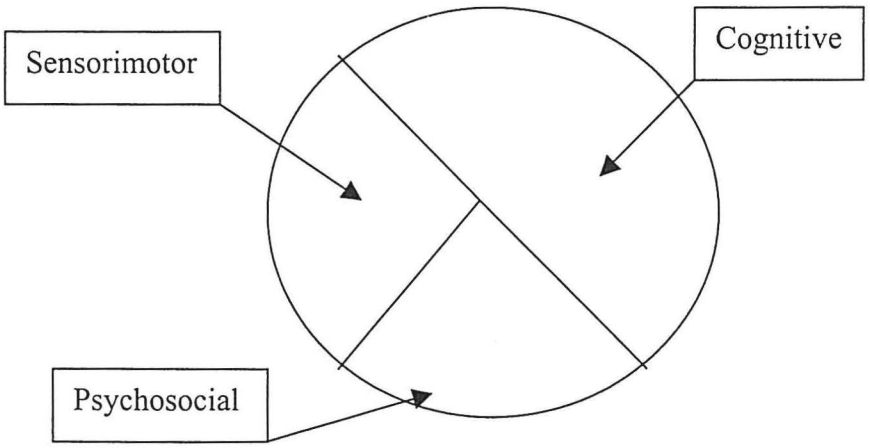
anxious about the paper, his psychosocial component also plays a role. His adaptation gestalt would look like this:

Figure 4: Adaptation Gestalt for a Student who is Not Nervous



Let us just consider for a moment that instead of being just a little nervous, Byron is very nervous because he has had difficulty with term papers in the past and has struggled to complete them on time. In this scenario his adaptation gestalt would look like this:

Figure 5: Adaptation Gestalt for Student who is Nervous



A combination of the parts of the adaptive response mechanism and the adaptational gestalt are used to formulate an occupational response. This response can either be effective or ineffective. As such, the occupational adaptation model identifies the next step in the process as the evaluation of the occupational response by the person (adaptive response evaluation subprocess) and by the environment (assessment of response outcome). The occupational response is judged against the criteria of efficiency, effectiveness, and satisfaction to self/society within in the person. At the same time, the occupational response is judged against the environmental aspects of the physical, social, and cultural components.

Once again, consider the student with the term paper. At this point in the process, Byron has finished his term paper and turned it in. He receives his paper back with a grade of A and positive comments from his teacher. His self evaluation may look something like this:

Figure 6: Student Relative Mastery

Criteria	**Outcome**
Efficiency	Efficiency lacked somewhat as he spent several hours running around his room and the dorm not accomplishing anything.
Effectiveness	The term paper is effective since he got his grade of an A.
Satisfaction to self/society	Satisfying to Byron since he got the A. Satisfying to teachers since he performed to their expectations of him being a good student in the class.

In this instance, Byron has developed relative mastery over his term paper. Even though he was not as efficient as he would have liked to be, he still accomplished what, for him, was his main goal – to get a good grade on his paper and subsequently in his

class. At the same time Byron is evaluating himself, the occupational environment is evaluating him. That evaluation may look like this:

Figure 7: Occupational Environment Evaluation of Student

Criteria	Outcome
Physical Environment	Byron was constrained by the abilities of his computer and workstation. In this instance, they were sufficient to enable him to meet his goal.
Social Environment	The social environment may not have been as supportive since Byron's roommate insisted on going to bed at 10:00 because he had a test the next morning. Byron had to move to another area to work on his paper.
Cultural Environment	The cultural environment of the university was supportive in this instance. The university expected him to maintain good grades to continue on in his education process which he was able to do.

After this self evaluation has occurred, the person must then integrate this adaptive response into his/her memory for future use. The occupational response is judged to be occupational adaptation, homeostasis, or occupational dysadaptation. The occupational environment also integrates this occupational response by having an influence on the occupational role expectations that are external to the person. In the case of the student, he was able to have occupational adaptation and complete his term paper successfully.

Schkade and McClung (2001) state that there are indicators that the occupational adaptation process is working: the client experiences increased relative mastery, the client demonstrates spontaneous generalizations to novel tasks, and the client initiates adaptations not previously seen or specifically suggested. Since our student did experience increased relative mastery in this scenario, the occupational

adaptation process is working. If the student is subsequently able to apply this process to other classes or other assignments, he would be experiencing the spontaneous generalizations that indicate the occupational adaptation process is working. The student making changes to his plan to write papers without suggestions from others also indicates the occupational adaptation process is working.

It is helpful to recognize that this process does not occur in isolation and it is likely that several courses of the process can be occurring simultaneously. Occupational adaptation is a normative process and can be applied to all types of situation where a person must make an adaptational response to an occupational challenge.

Appendix B

Occupational Therapy Initial Evaluation for Lymphedema

OCCUPATIONAL THERAPY INITIAL EVALUATION FOR LYMPHEDEMA

Name:_____DOB:_____MRN:_____

Physician:_____Onset Date:_____SOC Date:_____

OT Dx:_____

_____

Medical Dx:_____

_____

Frequency/Duration_____Date of Eval:_____

HISTORY:

Lymphological:_____

_____

_____

Past Medical Hx:_____

_____

_____

Medications:_____

_____

_____

Do medications currently include antibiotics/diuretics?_____

_____

Has patient ever taken any medications for lymphedema?_____

_____

Has patient ever had any of the following conditions:

Manual Lymphatic Drainage Contraindications: Untreated Cancer _____
Congestive Heart Failure _____
Acute Infections (with a fever) _____
Thrombosis (< 6 months) _____

Manual Lymphatic Drainage Precautions: Tuberculosis _____ Toxoplasmosis _____
Hyperthyroid _____ Chronic Infections _____ Nevus _____ Treated Cancer _____
Thrombosis (> 6 months) _____ Low Blood Pressure _____ Spastic Colon _____
Diabetes _____ Asthma _____ Radiation to the Abdomen _____
Skin disease on the affected limb (Cellulitis) _____

Are you (or could you be): Pregnant: Yes _____ No _____
Menstruating: Yes _____ No _____

Surgery Date:_____

_____

Accompanied Treatments:_____

_____

_____

- Radiation: Yes _____ No _____
  - If yes, how often and where applied:_____

    _____

    _____
- Chemotherapy: Yes _____ No _____
  - If yes, how many series:_____

    _____

    _____
- Reconstructive Surgery: Yes _____ No _____

EDEMA HISTORY:

Clinical Course: Acute _____ Chronic _____ Exacerbation _____

When did the edema start?_____

_____

_____

_____

_____

Does the patient have complications and secondary pathologies in the edema area?

Yes _____ No _____

- Describe:_____

  _____

  _____

  _____
- Describe the pain and location:_____

  _____

  _____

  _____
- When did it start?_____

  _____
- Pain Intensity Level: ___/10

Current Discomforts: Yes _____ No _____

- Describe:_____
- During the day:_____
- During the night:_____

Does the patient have any wound healing problems after surgery? Yes _____ No _____

- Describe:_____

_____

SENSORIMOTOR FUNCTIONING:

MMT: WNL ____ WFL _____ ABN _____

Proximal __/5 Distal __/5

ROM: WNL _____ WFL _____ ABN _____

Sensory testing: WNL _____ WFL _____ ABN _____

Coordination: WNL _____ WFL _____ ABN _____

Endurance: WNL _____ WFL _____ ABN _____

Edema: See attached measurement sheet.

- Describe any abnormal (ABN) scores noted in this section:_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

PYSCHOSOCIAL ISSUES:

Does patient identify any of the following feelings? Anxiety _____ Depression _____

Shock _____ Fear _____ Annoyance _____ Negative Body Image _____

Anger _____ Sexual Issues _____ Fear of being intimate with a partner _____

Strong emotions regarding being in public with swollen limb ____

Strong emotions regarding social activities with swollen limb _____

- Describe_____

  _____

  _____

  _____

  _____

Does the swollen limb interfere with cultural activities (either of ethnicity or environmental)? Yes _____ No _____

- Describe:_____

  _____

  _____

COGNITIVE ISSUES:

Does patient identify any of the following: Decreased memory _____ Problem solving issues _____

Is patient oriented to: Person _____ Place _____ Time _____

PAST CLINICAL TREATMENT FOR LYMPHEDEMA:

Has patient ever received treatment for lymphedema? Yes _____ No _____

- If so, did it include: Compression Garment _____ (class _____)

  Mechanical Pump _____ MLD _____ Compression bandaging _____

  Drugs _____ Surgery _____

INTENTION TO MANAGE LYMPHEDEMA:

Does patient intend to manage his/her lymphedema? Yes _____ No _____

- Describe _____

  _____

  _____

OCCUPATIONAL ENVIRONMENTAL ISSUES:

Does the patient identify difficulty with Self Care tasks? Yes _____ No _____

- Describe_____

_____

_____

_____

Does the patient have difficulty with Work tasks? Yes _____ No _____

- Describe_____

_____

_____

_____

Does the patient have difficulty with Leisure tasks? Yes _____ No _____

- Describe_____

_____

_____

_____

Are physical, social, and/or cultural issues identified as relate to any of the above?

Yes _____ No _____

- Describe_____

_____

_____

_____

REDUCTION OF FUNCTIONAL STATUS:

What activities/occupations does the patient feel he/she has lost due to the lymphedema?_

_____

_____

Which does the patient consider worse:

EDEMA _____ FUNCTIONAL REDUCTIONS _____

Patient goals:_____

_____

_____

SUMMARY/RECOMMENDATIONS:

PLAN OF TREATMENT/GOALS:
Patient will be seen _____ times per week times _____weeks to address the following issues:

_____ _____
Therapist Signature Date

I certify the need for these services furnished under this plan of treatment and while under my care.
FROM:_____ TO:_____

_____ _____
Physician Signature Date

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